Gaining in a Landscape of Loss:

The Experience of Learning and Using Mindfulness whilst Caring at the End of Life

BY

LINDA MAREE JAFFRAY

(Bachelor of Social Work)

School of Medicine, College of Health and Medicine

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- Linda Jaffray, School of Medicine (Candidate)
- Heather Bridgman, University of Tasmania (Author 1)
- Miranda Stephens, University of Tasmania (Author 2)
- Timothy Skinner, Charles Darwin University (Author 3)

The candidate was the primary author of the published paper, 'Evaluating the Effects of Mindfulness-based Interventions for Informal Palliative Caregivers: A Systematic Literature Review', located in Appendix 2. The candidate, with author 3, contributed to the conception and design of the research project. The candidate contributed 90% to the planning, execution, drafting and editing of the paper. Authors 1, 2 and 3 supported the candidate with the process of assessing studies for inclusion in the review, proofreading and editing the paper ready for publication.

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'The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University.

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Abstract

Informal palliative caregivers, or those caring for a terminally ill family member or friend, are critical to the provision of quality, sustainable end-of-life care. The support provided by these caregivers is increasingly important, considering an ageing population, higher levels of disease burden and increasing healthcare demands. Adverse impacts of end-of-life caregiving on caregiver health and wellbeing, however, are substantial and well-documented. Despite a twenty-year global consensus calling for more evidence-based caregiver support interventions, patient-focused palliative care research, practice and policy have predominated, overshadowing a focus on caregivers. Evidence-based caregiver support therefore, remains narrow in relation to caregivers' holistic unmet needs, and experiences of caregivers 'feeling invisible' persist across studies.

Emerging research indicates positive potential of contemplative self-care or stress-management approaches, such as mindfulness-based interventions (MBIs), to address the void of holistic care approaches. However, there is a lack of in-depth, qualitative understanding and conceptualisation of the process and effects of learning mindfulness in this setting.

This qualitative study provides the first in-depth theoretical understanding of the experience of learning and using a mindfulness-based approach, whilst caring for a family member or friend at the end of life. Employing a constructivist grounded theory methodology (Charmaz 2006), semi-structured interviews were conducted with mindfulness facilitators (n=12) experienced in teaching mindfulness to informal palliative caregivers. In-depth interviews were also conducted with informal palliative caregivers (n=8) who had

learnt and used mindfulness in caregiving. Data was analysed concurrently with, and informed, data collection, progressing through the cycles of initial, focused and theoretical coding.

Study findings have led to the development of a new grounded theory model: 'The Experience of Learning and Using a Mindfulness-based Approach in End-of-life Caregiving: A Theoretical Model'. Findings identified multiple, interwoven benefits, including mindfulness as an empowering new form of respite and a way to shift caregiver reluctance to care for themselves. This study also challenges assumptions and practice regarding prescriptive, intensive approaches to mindfulness training advanced in other settings, advocating that there is no 'one size fits all' model.

This conceptual understanding of the process, outcomes and challenges of learning mindfulness as an informal palliative caregiver can inform the development and evaluation of MBIs in this setting and has significant implications for practice and further research.

List of Key Acronyms

AASW	Australian Association of Social Workers
ABS	Australian Bureau of Statistics
ACSQHC	Australian Commission on Safety and Quality in Health Care
ACT	Acceptance and Commitment Therapy
AIHW	Australian Institute of Health and Welfare
ALS	Amyotrophic Lateral Sclerosis
APA	Australian Psychology Association
ASGC-RA	Australian Standard Geographic Classification – Remoteness Areas
CASP	Critical Appraisal Skills Programme
CBT	Cognitive Behavioural Therapy
CGT	Constructivist Grounded theory
COPD	Chronic Obstructive Pulmonary Disease
DBT	Dialectical Behaviour Therapy
EBT	Existential Behaviour Therapy
GT	Grounded Theory
LGBTI	Lesbian, Gay, Bisexual, Transgendered, Intersex
MBA	Mindfulness-based Approach
MB-EAT	Mindfulness-based Eating Awareness Training
MBCP	Mindfulness-based Childbirth and Parenting
MBCT	Mindfulness-based Cognitive Therapy
MBIs	Mindfulness-based Interventions
MBSR	Mindfulness-based Stress Reduction
MBRP	Mindfulness-based Relapse Prevention
MiCBT	Mindfulness-integrated Cognitive Behaviour Therapy
MODEL	Mindfully Optimizing Delivery of End-of-Life (MODEL) Care intervention
MORECare	Methods of Researching End-of-Life Care
MND	Motor Neuron Disease
MS	Multiple Sclerosis

NICE	National Institute for Health and Care Excellence
PCA	Palliative Care Australia
PeolcPSP	Palliative and End-of-Life Care Priority Setting Partnership
RCT	Randomised Controlled Trial
SPCS	Specialist Palliative Care Service
WHO	World Health Organisation

PART I: ORIENTATION TO THE STUDY

This thesis is broken up into five key parts. Part I situates myself in relation to this study and introduces the research. This is followed by Part II 'Background', Part III 'Study Methodology' and Part IV 'Study Findings'. The thesis concludes with Part V, 'A Grounded Theory Model and its Implications for Research and Practice' which contains both the discussion and conclusion.

This, Part I of the thesis, is comprised of two key sections. The first, 'Situating the Researcher', will outline my motivation and interest in the topic and a commitment to research reflexivity throughout the research process. I use the first-person voice in this section to position myself as a researcher, as opposed to receding as a distanced, anonymous author (Mills, Bonner and Francis 2016a). This is consistent with the qualitative and constructivist approach adopted in this research, which advocates the importance of positioning a researcher's worldview and experience in relation to their study. Whilst traditionally this may be elucidated in a preface, it was a considered decision to attend to the positionality of the researcher within the body of this thesis. This is due to an ongoing process of reflexivity throughout all phases of the research, as opposed to only attending to researcher motivation, interest in and experience of the topic, prior to conducting the study.

Secondly, this part of the thesis contains Chapter One: 'The Introduction', which will introduce the research problem, the context of the study, its aims and research design. It will outline the thesis structure and explain the key concepts used throughout the thesis.

SITUATING THE RESEARCHER

My interest in exploring the topic of mindfulness for informal palliative caregivers is informed by my own experience of learning mindfulness between two significant life events; after the death of my father and before the death of my grandmother four years later. In addition, my professional background as a palliative care social worker further influenced my interest in this topic. As a qualitative researcher it is important to make transparent how these events have shaped my reasons for embarking on this research and the methodological decisions I have made in the process.

My Personal Experience

'All the leaves will soon be gone and so will I'

When my youngest son, Cooper, was only three-months old, my Dad was diagnosed with metastatic bladder cancer. The cancer had spread to his liver. I knew enough from experience of working in palliative care that Dad wouldn't be alive to see Cooper's first birthday and he wasn't. I was very close to my Dad. He had been such a big force in my life. He was there for every big moment in my life: the joyous moments, the disasters and all the ordinary days in between. He was the person I would go to for advice. He was the person who would champion me when my own belief in myself faltered and he was the practical hands that could fix anything that was broken, except he couldn't fix this situation.

It seemed so unfair. I couldn't get my head around the fact that I was going to lose him and that my son would never know his grandfather as I had hoped that he would. Despite my years of working in palliative care and seeing people navigate this very journey repeatedly, I

couldn't imagine how I was going to get through this. In his lucid moments, Dad would notice how dwarfed and helpless I felt at times in relation to all that was happening and hurtling towards us. He would tell me "*You have a lot of strength girl and you will find it when you need to.*"

I would sit with my Dad for hours in his hospital room, trying to settle my little baby to sleep so that I could talk with him. We had always talked about everything, but this was getting harder to do. It was hard not only because I was trying to juggle the beginning of Cooper's life, with the end of Dad's life, but also because Dad was in so much pain. I don't think I have ever seen anyone suffer so much at the end of life. Despite the increasing cocktail of medications that they pumped into Dad's syringe driver, the pain never went away. He would talk about wanting all the pain to stop, for it all to be over, for death to come. But in other moments he wanted more of life, more moments with us and wished death to slow its advance towards him. If this wasn't enough, his delirium would descend like a thick curtain, cutting Dad off from us, cruelly stealing what precious time we had left. He described this as being caught between two worlds. He said that each world had different events unfolding and different people in it. He was never quite sure who belonged to which world and to which world he belonged. Sometimes the curtain would lift, and the delirium would clear long enough for us to have an important and heartfelt conversation. These were precious moments.

One particular day I was sitting with Dad in his hospital room. It was autumn. We were both looking out of his window which overlooked a sloping street-scape of weatherboard houses and large, English trees. It was the type of autumn morning in Tasmania that began with a thick frost, but cleared to promise a bright, blue-skyed day. The leaves on the trees were

changing, exploding into spectacular bursts of brilliant oranges, sunburnt reds and yellows. We both loved nature and loved the changing seasons which were always really marked in Tasmania. It was quite a spectacular scene and a welcome feast for the heart and the spirit, in stark contrast to the white clinical environment of his hospital room. After a long time of silence, Dad looked at me and said, "*Soon all those leaves will be gone and so will I."* His words hung heavily in the room. They carried a painful realisation of how quickly time was leaking through our fingers. They stirred in me a rising sense of dread about how quickly Dad would be swept towards the end of his season: the last season that we would ever share together in this world. His words encapsulated our painful reality in a strangely beautiful but brutal way. He saw my distress, acknowledging it by moving his hand to rest on mine. We sat together in silence for a little while because there were no words. There was nothing to say to make it better, easier or different, no matter how much we wanted it to be so. We both sat with this heavy realisation.

The longer we sat there, the more I felt helpless, overwhelmed and scared in the face of what was coming. I said to him, *"I miss you already"* and I remember his poignant reply. He looked at me kindly, squeezed my hand and said, "*I'm still here girl. I'm right here. Be here with me now."* There was such power in his words. I knew he was right. I shouldn't be spending what precious time I had left thinking about what lay ahead for him and for me. I knew grieving his death before he had died made no sense. I was still going to have to do it all over again when the time came.

I desperately wanted to find a foothold or something to grab onto that would help steady me and stay in the moment with Dad, to really be there in what precious time I had left with him. But how to do that? I had no idea. What was it that I could grab onto to stop myself

from being swept away in torrents of emotions and imagined catastrophes? I had a large store in my mind of images and events that I had seen other families go through in palliative care: the worst kinds of events and the pain that people had endured. I had seen what that looked like, the toll it took. It seemed so simple “Be here with me now”, but it was so hard to do.

I tried the best I could, but it was hard to stay in the moment with him. I found myself pulled away again and again by nurses coming and going, my little boy waking for a feed, my other children needing me to go home and be a mum to them. I was swept away in Dad’s process too, his coming in and out of consciousness, his escalating pain and increasing frailty. In the chaos and grief of it all, I felt swamped and managed only the briefest moments of being fully present with him. I wrote the following poem in one of my dark and helpless moments as I sat beside my Dad in his final week.

What to do with this pain?
This gut-wrenching grief
that tears away the fibres of my world.
This crushing sense of impotence
to ease his grief, his suffering
and my own?

What to do when there are no more words to speak?
No more actions to take.
No arsenal to help him in his slow
and tortured struggle
from his failed body,
this world
and us.

What to do?
In this void – this betwixt space
between having my father,
yet not having him,
his essence wrenched away,
first by delirium,
then by death's slow rattling approach.

How do I steady myself
in the face of this groundlessness?
Bereft of any 'sticking place',
something to hold on to.
I have nothing –
and I am swept along,
tumbled and thrashed,
in the wild, foaming rapids of grief.

(Linda Jaffray, 2010)

A year after Dad died, I came to learn mindfulness. I undertook a free 8-week mindfulness-based stress reduction course (MBSR) funded through a local primary health organisation. It was run by a psychologist who was an accredited mindfulness teacher.

I had been keeping up a regular mindfulness practice for about three years when my loved grandmother became terminally ill and died. My experience of Gran's illness and death was very different to my experience with my Dad. I felt that mindfulness was a big part of what made that difference in helping me to meet the challenges of caring for and

being with Gran, and how I navigated my grief and bereavement. Mindfulness enabled me to grab the edges of a pontoon, for want of a better word, that I could pull myself up onto, out of the river, out of the rapids, even if only for a few moments, out of the swirling thoughts, feelings and fear of what was coming. It enabled me to spend time with her in the moment, with whatever was happening. These were precious moments. Mindfulness offered me a tool that I had within me, which I didn't have and wished I had, in my experience with Dad.

I began wondering if mindfulness could help other family caregivers in palliative care. Could it help people meet the challenges in caregiving? Would it help people to create more moments of being 'fully present' with their significant others, while they still had them, rather than being swept away in concerns about what was to come, or getting in stuck in 'what if'? Would learning mindfulness amidst this storm just be too difficult? Would it create more stress? These questions, born from a deeply personal experience and from my professional experience as a palliative care social worker outlined below, seemed important. The curiosity to explore these and other spinning questions about mindfulness in the setting of informal palliative caregiving compelled me to set out on the long, difficult and rewarding journey that became my PhD.

My Professional Background

My professional background is social work. Prior to commencing this research, I worked for 20 years as a social worker. Twelve of those years were spent as a specialist palliative care social worker social worker in a rural / regional community-based palliative care service on the northwest coast of Tasmania. In this role, I worked with hundreds of families, during what was often the most difficult and emotionally challenging period of

their lives. I was always struck by the huge task that carers take on to meet the complex and changing needs of a family member or friend with a palliative illness, all the while, grieving themselves. I came to observe their resilience and strength, whilst they worked through the most confronting of experiences. However, I also was very aware how they tended to neglect their own needs. I always felt that from a service perspective, patient needs were the primary focus, largely because of resource constraints. While the service I worked in provided information and practical support to help with tasks of caring, the provision of emotional and psychological support for caregivers was limited in my opinion.

I recognise how the discipline of social work and a strengths-based perspective has framed my view of palliative care practice, policy and research, and specifically, the conduct of this study. At its heart, social work is a discipline concerned with empowering people to identify and work towards achieving what is important to them. Social work regards people as the experts on their own lives and works in empathic and collaborative ways to help them access the resources and opportunities that will facilitate the realisation of important needs and goals. However, the social work view is broader than the individual in isolation of their social environment (Banks 2012; Payne 2015). Social work is interested in the intersection between people and society, recognising that personal challenges reflect and are influenced by the political, cultural and social contexts in which they live (Healy 2014). This resonates strongly with the qualitative research approach of seeking to understand context and meaning from the perspective of those living through their experience. Social work adopts a strong commitment towards social justice. It is cognisant of power and the ways in which people can experience disadvantage and discrimination and works to bring about change to redress these inequities (Australian Association of Social Workers (AASW) 2010; Hare 2004). This framework has attuned me to the marginalisation and silence of

informal palliative caregivers in the literature, and arguably within practice. Further, it has served as a powerful impetus to my interest in recruiting and amplifying the caregiver voice to help inform supportive caregiver interventions.

The strengths perspective is an approach used within the discipline of social work. It advocates a view of people as being resilient and resourceful (Saleeby 2012), with a lived history of drawing from a repertoire of internal strengths and skills, as well as external supports to meet the stressors and challenges in their lives (Hughes 2015). The strengths perspective is a counterbalance to the common biomedical and pathological ways of looking at people, which typically emphasise deficits, risks and aspects of people and their lives that are fractured or flawed. The strengths perspective informed my interactions with interview participants, particularly with caregiver participants. Specifically, it guided the way in which I addressed issues of power and was attuned to participants' strengths which were frequently buried under more dominant stories of self-criticism. The strengths perspective also supported transitioning participants out of the interview space, which often had involved talking about intense and difficult experiences. This will be detailed more fully in Chapter 4 'Research Design and Methodology'.

CHAPTER 1: INTRODUCTION

1.1 Chapter Introduction

Following from the previous section in which I introduced myself and my relationship to this present study, this chapter introduces the study itself. This chapter, the introduction, presents an overview of the study including its context, the research problem being addressed, the study aims and research design. The chapter also defines key concepts used in this thesis and provides a brief overview of the structure and organisation of the thesis.

1.2 Study Context

> *There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers and those who will need caregivers* (Rosalynn Carter 1997).

These words spoken by Rosalynn Carter, a pioneering caregiver advocate, President of the Institute for Caregiving and former First Lady, offer an insightful and fitting reflection of the universal experience and significance of the informal caregiving role. Throughout the developed world, people are living longer, with a greater level of disease burden (World Health Organisation 2018; Palliative Care Australia 2012; Australian Institute of Health and Welfare 2018a). This gives rise to an increasing number of people with complex end-of-life care needs requiring substantial support from both formal (services) and informal (kin and social networks) sources. The World Palliative Care Alliance and the World Health Organisation (2014) estimates that 40 million people world-wide require supportive and palliative end-of-life care. Within Australia alone in 2017, of the 165,000 deaths recorded,

75% were estimated to have been attributable to chronic, progressive or palliative disease (Australian Bureau of Statistics, 2017). This corresponds to over 123,000 people who could have been eligible for palliative care services (Palliative Care Australia 2018b). The Global Atlas of Palliative Care at the End of Life describes palliative care as an approach that:

> Improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual Palliative Care (World Palliative Care Alliance & World Health Organisation 2014, p 5).

It is now acknowledged that the demand for palliative or end-of-life care well exceeds the care resources available within formal services (Deloitte Access Economics 2015). For example, it is estimated that 90% of people in the terminal phase of a palliative illness, in Australia, spend the majority of time at home cared for by a family member or friend (Palliative Care Australia 2012, p 139). Support from friends and family, often referred to as informal palliative caregivers, is therefore instrumental in people receiving compassionate and skilled care at the end of life, and the opportunity to live as long as possible in their home environment (Alonso-Babarro et al. 2011; Gomes & Higginson 2008). Informal palliative caregivers are increasingly recognised as a critical economic resource (Round, Jones & Morris 2015). If formal care was required to substitute the contribution of informal palliative caregivers to end-of-life care in Australia, it is estimated to cost the equivalent of 3.8% of the gross domestic product, or 60% of the health and social work industry (Deloitte Access Economics 2015).

Providing end-of-life care to a family member or friend does not come without considerable cost to the health and wellbeing of caregivers themselves. Documenting and understanding the adverse impacts of informal caregiving has been the primary focus of the field of informal palliative caregiver research. However, such focus has been slow to emerge and has been largely overshadowed by patient-focused palliative research (Hudson, Remedios & Thomas 2010). The adverse effects of end-of-life caregiving on caregivers physical, psychological, emotional, social and financial resources are now well understood (Hudson et al. 2015; Stajduhar 2013, McDonald et al. 2018). Many studies reveal that caregivers can exhibit a higher rate of distress and mental health symptoms than patients themselves (Aoun et al. 2005a; Hudson et al. 2015). In response, there is a global consensus of the need to provide effective support to informal palliative caregivers, not only to reduce negative effects, but also to enhance the possibility of positive and rewarding caregiving experiences at the end of life (Dionne-Odom et al. 2017b; Harding et al. 2012a; Payne 2010).

1.3 The Research Problem

Despite the instrumental role of informal palliative caregivers in end-of-life care and a universally recognised need to provide effective caregiver support, intervention research continues to lag behind descriptive-based research documenting the experience and impact of caregiving (Boersma et al. 2017; Henwood, Larkin & Milne 2017). Of the existing informal caregiver intervention research undertaken, there has been an overwhelming focus on a narrow range of interventions that are designed to increase caregiver capacity and preparedness to care for a terminally ill family member or friend (Harding et al. 2012b; Pope et al. 2017). A range of methodological issues preclude a clear determination of what interventions work best for whom, in what format, how and why. Psycho-educational-based

support interventions have been the most frequently researched and demonstrate the most consistent effect for increasing caregiver preparedness and self-efficacy for caring for others (Chi et al.2016; Elvish et al. 2013; Harding et al. 2012b; Ussher et al.2009). However, this focus has led to a dearth of research that has specifically focused on interventions that aim to increase the capacity of caregivers to consider and take care of themselves and their own needs (Dionne-Odom 2017a). Further, interventions that specifically focus on the health and wellbeing of caregivers as persons in their own right, separate from and irrespective of patient benefit, remain wanting (Pope et al. 2017).

Informal palliative caregivers continue to experience adverse impacts of caregiving across psychological, emotional, physical, social and financial domains (Aoun et al. 2005c Stajduhar et al. 2010; Williams et al. 2013). The range of informal palliative caregiver support interventions remain narrow in relation to these unmet holistic caregiver needs (Harding et al. 2012b). For example, exploration and development of proactive, preventative support approaches, rather than those marked by a 'crisis-orientated' focus, are strongly advocated (Grande et al. 2009; Dionne-Odom 2017a). Additionally, interventions that actively recruit and cultivate caregiver strengths and enhance self-determination in responding to end-of-life caregiving challenges, rather than ascribing expertise to service providers to 'educate', 'fix' or 'treat' informal caregivers are also called for (Grande et al. 2009; Hughes 2015; Ugalde 2011).

Further, the field of caregiver intervention research, in adopting predominantly quantitative approaches, has only acquired limited understanding of caregivers' lived-experience, and their perspectives of interventions. This has implications for guiding intervention development and application in a way that is feasible, acceptable and effective,

in the complex and intense setting of end-of-life caregiving. As a result, descriptions and metaphors of informal palliative caregivers feeling invisible or 'caring in the dark' (Andershed & Ternestedt 1998) and expressing 'a desire to be seen' (Linderholm & Friedrichsen 2010) persist both in research and practice, warranting urgent redress.

Mindfulness-based interventions (MBIs) are holistic, empowering approaches to self-care and stress management with increasing evidence of efficacy across diverse populations, including professional care providers. The research field investigating the application, feasibility and effectiveness of MBIs for informal palliative caregivers in contrast, is still in its infancy. Findings suggest that MBIs may offer an empowering, proactive approach to cultivating informal palliative caregiver capacity to care for themselves and their own needs, and to manage the personal impacts associated with caring for a family member at the end of life (Jaffray et al. 2016; Dharmawardene et al. 2016). However, there is a need to carefully consider and understand what learning mindfulness in this setting may involve, not only in terms of potential benefit but also potential risk of adverse effect and the elements required to mitigate these (Jaffray et al. 2016). Existing research has focused on quantifying the effects of learning mindfulness in informal palliative caregiving. Of the small number of mixed method studies, the focus has been on description as opposed to offering interpretive or theoretical understanding of what it is like to learn and use mindfulness in end-of-life caregiving. As a result, developing an in-depth conceptual understanding of how caregivers experience learning and using a mindfulness-based approach in this setting has been a neglected field of inquiry. Further, what it means and what MBI models may need to look like in this setting have not been researched in-depth to date.

1.4 Study Aims

To address the research problem, this present study aimed to:

> *Provide an in-depth, conceptual understanding of the experience of learning and using a mindfulness-based approach whilst caring for a family member or friend at the end of life*.

In this aim, this study seeks to identify how learning and using a mindfulness-based approach in the context of end-of-life caregiving is experienced and described. It aims to examine the potential for value and benefit, as well as adverse effects and possible harm. It also seeks to explore and understand the key elements in developing and providing mindfulness-based approaches for informal palliative caregivers and why these elements are regarded as important.

1.5 Research Design

This study adopted a qualitative research approach, using a constructivist grounded theory methodology (Charmaz 2006). Based on the work of Kathy Charmaz, constructivist grounded theory is an increasingly used methodological approach in health research, particularly within the fields of chronic illness and palliative care (Charmaz 2006; da Silva Barreto, Garcia-vivar & Marcon 2018). The methodology is well suited to research where the phenomenon under study is complex, poorly understood, and as such, does not easily lend itself to be investigated by a quantitative approach to inquiry (Padgett 2012; Holloway 2005).

This study employed semi-structured and intensive interviews with 20 research participants including mindfulness facilitators (n=12), who had taught mindfulness to

informal palliative caregivers and informal palliative caregivers (n=8) who had experienced learning and using mindfulness during end-of-life caregiving. Constructivist grounded theory enabled the development of a theoretical model to explain the experience of learning and using a mindfulness-based approach whilst caring for a family member or friend at the end of life.

1.6 Study Significance

With projected demographic trends of increased numbers of people with complex palliative needs, supporting informal palliative caregivers will become increasingly critical (Palliative Care Australia 2012). Support approaches need to extend beyond equipping caregivers to provide skilful and compassionate care to their significant other at the end of life. Interventions that enable caregivers to respond effectively to the personal impact of caregiving are required, along with approaches that collaborate with caregivers to develop and evaluate such approaches.

In adopting a qualitative, constructivist grounded theory approach to exploring the experience of learning and using mindfulness in end-of-life caregiving, this study offers several significant contributions to the field of informal palliative caregiver intervention research. Firstly, methodologically, this study demonstrates the feasibility and value of recruiting caregivers to informal palliative caregiver research, challenging several assumptions across both the mindfulness and informal palliative caregiver literatures. Secondly, it shines a light on caregivers' lived experience and meaning-making of having participated in MBIs and what it is like to use the acquired skills in facing end-of-life caregiving challenges. In presenting the views of caregivers, this study answers a growing call in the field to invite caregivers to 'come out of the shadows' and help inform the

development of support interventions in this setting by contributing their experience and voice (Gysels et al. 2013; Steinhauser et al. 2006). This includes elucidating the benefits or outcomes valued by caregivers themselves and what they mean, rather than presupposing what is beneficial and why. Thirdly, this study widens interventions from those traditionally offered to caregivers, by recasting emphasis on empowering, proactive and holistic based approaches. This contrasts with longstanding and enduring risk and disease-based models of reducing negative symptoms and effect (Dionne-Odom 2017a; Hughes 2015; Johnston et al. 2012). Specifically, this study lends support to developing interventions which support caregivers to cultivate their own inner resource to manage distress and difficulty and to realise more positive moments of end-of-life caregiving and enhanced wellbeing.

1.7 Key Terms in the Thesis

Several key terms and concepts used frequently within this thesis. These are defined and operationalised below for clarity and understanding.

Informal palliative caregiver: Someone who provides for the emotional, physical or practical support needs of a family member or friend with a palliative illness, in an unpaid capacity, usually from the basis of kinship or social connection.

A palliative illness: 'An active, progressive, advanced disease which has little or no prospect of cure' and expected to lead to death as a direct consequence of this disease (Palliative Care Australia 2018a, p 5).

End of life: The term 'end of life' is variably used and defined. This thesis draws on the consensus statement of the Australian Commission on Safety and Quality in Health Care

(ACSQH) 2015 and the Australian Institute of Health and Welfare (AIHW) 2016, to define end of life as the last 12-months of life.

'Care recipient' or 'significant other': Refers to the family member or friend who is experiencing the palliative illness and for whom the informal palliative caregiver is caring. These terms are considered preferable to the term 'loved one'. Whilst 'loved one' is commonly used in palliative research, it can wrongly assume a quality of relationship or affection that may not be true of all caregiver-care recipient connections.

Mindfulness-based interventions (MBIs): Facilitated programs delivered in several sessions over time, that aim to teach participants, through meditation practice, how to cultivate attention on the present moment and observe the constantly changing field of thoughts, feelings and sensations without judging or seeking to alter the experience. Mindfulness-based interventions are often described as being derivative from the insight tradition. Mindfulness programs are frequently delivered as a group-based intervention with requirements for home practice, both formally, in terms of undertaking meditation exercises and informally, as people go about their activities in daily life. However, mindfulness might also be delivered in a one to one setting or a combination of group and individual sessions.

Mindfulness-based approaches: The research literature uses the terms mindfulness-based interventions and mindfulness-based approaches interchangeably. In latter parts of the thesis the term 'mindfulness-based approaches' is more frequently used. The reason is that this term better reflects the findings of the flexible and diverse ways in which caregivers learn mindfulness, outside of the more traditional structured programs.

Mindfulness facilitators: Refers to individuals who have undertaken training in mindfulness, have an ongoing mindfulness self-practice and who deliver mindfulness training to others.

Value: Is taken to mean any positive or beneficial occurrence or outcome which relates to the learning of mindfulness in the palliative caregiving and bereavement settings and includes references to what benefit/s mean.

Risk: Is taken to mean any potential of MBIs to cause harm or adverse consequences to participants. The rationale for inquiring into the potential for risk or negative effects of learning mindfulness in the caregiving context is anchored in a concern to bring a holistic lens to inquiry, as opposed to only focusing on potential value and benefit.

Participants: Is the term used in the results section of this thesis when referring to findings that reflect the data of both sets of interview participants in this study: the mindfulness facilitators (n=12) and informal palliative caregivers (n= 8). Where findings pertain to facilitator data only, the terms 'mindfulness facilitators' or 'facilitators' are used. When findings relate only to caregiver interview participants, it is indicated that this data was expressed by 'caregivers'.

1.8 Thesis Structure

This thesis is organised in five key parts, consisting of nine chapters. Part I, '*Orientation to the Study'*, situated myself as the researcher and the current chapter, Chapter One, 'Introduction', which has provided the study context, its aims and significance, and introduced the research design. It also defined the key terms used in this thesis.

Part II of this thesis, '*Background*', comprises two literature review chapters. The first, Chapter Two, 'Informal Palliative Caregiving: A Review of the Literature', provides an overview of the diverse and ill-defined informal palliative care literature. Current understanding of the role, profile and contribution of informal palliative caregivers in end-of-life caregiving and the personal impact of providing this complex, multifaceted care is provided. Further this chapter examines the range, feasibility and effectiveness of caregiver support interventions, identifying a number of key gaps in understanding and requirements for future research. Key among them is the need to develop and trial interventions that have an explicit focus on supporting multidimensions of caregiver health, wellbeing and self-care. Chapter Three, 'Mindfulness-based Interventions for Informal Palliative Caregivers: A review of the Literature', reviews the mindfulness-based intervention literature broadly, then specifically for informal palliative caregivers. This chapter reveals that exploring the effects of MBIs in end-of-life caregiving is a very new field of enquiry. The dearth of qualitative research and the development of an in-depth conceptual understanding of the experience of learning and using a mindfulness-based approach, underpins the focus of this present study.

Part III, '*Study Methodology'*, contains Chapter Four, 'Research Design and Methodology'. This chapter provides a detailed and transparent account of the research

design, methodological approach, ethical considerations, methods of recruitment, data generation and analysis used in this study. Specifically, it explains and justifies the use of a qualitative research approach and constructivist grounded theory methodology congruent with the central aim of this study: to develop an in-depth, conceptual understanding of the experience of learning and using a mindfulness-based approach in end-of-life caregiving. Detailed explanation and evidence of the data analysis process and grounded theory model development are also provided.

Part IV of this thesis, '*Study Findings'*, comprises three chapters detailing the qualitative findings of the 20 participant interviews undertaken in this research. The first of the findings' chapters, Chapter Five, 'Experiencing a World Disrupted: The Context and Characteristics of End-of-life caregiving', depicts what it is like to care for a significant other at the end of life. Findings of caregiving as akin to landing in an unexpected, disorientating and loss-filled landscape are presented, along with the challenges involved in navigating and adjusting to a disrupted world. Chapter Six, the second findings chapter explores 'The Process of Learning and Using Mindfulness in a Disrupted World'. It presents what it is like to learn and use a mindfulness-based approach in the complex end-of-life caregiving setting. It discusses issues of facilitating caregiver engagement, supportive factors and managing challenges. In addition, it considers potential adverse effects. Chapter Seven, 'Gaining in a Landscape of Loss: The Value and Benefit of Mindfulness in End-of-life caregiving', is the final findings chapter in part IV of this thesis. Chapter Seven provides a rich account and conceptualisation of the benefits and value experienced as a result of learning and using a mindfulness-based approach in the disorientating, caregiving landscape. Specifically, it presents five key categories of benefit and distils what these benefits have meant in such an intense and challenging experience of end-of-life caregiving.

Part V in this thesis, '*A Grounded Theory Model and its Implications for Research and Practice',* includes Chapter Eight, 'Discussion', and Chapter Nine, 'Conclusion'. Chapter Eight, synthesises and discusses the findings of this study in relation to the research questions and the existing literature. An integrated theoretical model to explain the experience of learning and using a mindfulness-based approach in end-of-life caregiving is presented. This model comprises the findings of three overarching themes and their attendant categories: 'Experiencing a World Disrupted: The Context and Characteristics of End-of-life caregiving'; 'The Process of Learning and Using Mindfulness in a Disrupted World' and 'Gaining in a Landscape of Loss: The Value and Benefit of Mindfulness in End-of-life caregiving'. Chapter Nine, the Conclusion, discusses the contribution this study and its interpretive model makes to new knowledge. The implications of the study for clinical practice and further research are advanced, along with a critical reflection of the strengths and limitations of this study. The chapter and thesis conclude with a final personal reflection. A visual depiction of the structure of this thesis is provided in Figure 1.

The Harvard referencing system has been employed in this thesis.

OVERVIEW OF THE THESIS STRUCTURE

PART I: ORIENTATION TO THE STUDY

- Situating the Researcher
- Chapter 1: Introduction

PART II: BACKGROUND

- Chapter 2: Informal Palliative Caregiving: A Review of the Literature
- Chapter 3: Mindfulness-based Interventions for Caregivers: A Review of the Literature

PART III: STUDY METHODOLOGY

- Chapter 4: Research Design and Methodology

PART IV: STUDY FINDINGS

- Chapter 5: Experiencing a World Disrupted: The Context and Characteristics of End-of-Life caregiving
- Chapter 6: The Process of Learning and Using Mindfulness in a Disrupted World
- Chapter 7: Gaining in a Landscape of Loss: The Value and Benefit of Mindfulness in End-of-Life caregiving

PART V: A GROUNDED THEORY MODEL AND ITS IMPLICATIONS FOR RESEARCH AND PRACTICE

- Chapter 8: Discussion
- Chapter 9: Conclusion

Figure 1: Overview of Thesis Structure

PART II: BACKGROUND

Part II of this thesis consists of two literature review chapters. The first of these, Chapter Two, reviews the informal palliative caregiving literature. Chapter Three moves to review the mindfulness-based intervention research and its application and effect specifically, in the context of informal palliative caregiving, specifically. Together, these reviews set the scene for the focus of this present study.

Before these chapters are presented, the section below provides a brief overview of the approach taken to review the respective literatures, as these differ in important ways. This description makes transparent and defensible the methodology for reviewing and synthesising both the informal palliative caregiving and mindfulness literature bases, which are both dispersed and frequently ill-defined.

Approach to Reviewing the Informal Palliative Caregiver Literature

Two approaches were used to review the informal palliative care literature, presented in Chapter Two. The first approach could be described as an 'overview'. According to Grant & Booth (2009, p. 99) in their typology of reviews, an overview is 'a comprehensive summation of a topic area', in which the body of literature and its central characteristics are described. The electronic databases of MedLine, PubMed, CINHAL, PsycINFO and Google Scholar were searched using a combination of key words. Caregiver terms included: 'caregiver' OR 'carer' OR 'informal carer' OR 'family carer' OR 'care*'. Palliative search terms included 'palliative', OR 'palliative care', OR 'end of life' OR 'terminal' OR 'dementia' OR 'advanced cancer', OR 'heart failure' OR 'COPD', OR 'ALS' OR 'MND' OR

'MS'. The published articles were reviewed in respect to their focus (i.e., describing the caregiver role, identifying the impact of caregiving) and the type of research approach utilised (qualitative and quantitative). This aimed to provide an overview of a very ill-defined and widely dispersed body of informal palliative caregiver research.

To more closely review the informal palliative caregiver intervention literature a 'systematised approach' was used to investigate and retrieve relevant caregiver intervention studies. A systematised review, commonly conducted in postgraduate studies, is described as an attempt to incorporate several key elements of a systematic review process to comprehensively search for and critically evaluate existing research evidence (Grant & Booth 2009, p 102). The following intervention search terms were added to the previously outlined search strategy: 'interventions', OR 'approaches', OR 'programs' OR 'programmes', OR 'psychosocial' OR 'psychoeducation' OR 'social support' OR 'counselling' OR 'therapy'. The interventions of focus in this review were psychosocial approaches designed to support caregivers and which are instituted in addition to standard care. Psychosocial intervention is a large umbrella term encompassing a range of interventions concerned with a non-medical, non-pharmacological, non-physical approach to support (Galway et al. 2012). Findings of the literature review are presented in narrative form within this thesis.

Approach to Reviewing the Mindfulness-based Intervention Literature for Informal Palliative Caregivers

The review of the Mindfulness-based intervention literature in Chapter Three parallels the approach used in reviewing the informal palliative caregiver literature. An 'overview' of the mindfulness literature was conducted to identify and provide a broad overview of the field of mindfulness research. This approach to reviewing the literature provides a useful summation to those coming to understand the topic area for the first time (Grant & Booth 2009, p 99). This was followed by a more focused, systematised review. As detailed in Chapter Two, a systematised review incorporates a number of key elements of a systematic review process to comprehensively search for and critically evaluate existing research evidence (Grant & Booth 2009, p 102). The systematised review process as undertaken in this study included a comprehensive and systematic search strategy, that was sufficiently detailed to enable replication by others and which examined study quality and methodological limitations. Findings have been presented, both in narrative and tabular form, and a determination made in terms of what can be concluded from existing research, as well as the remaining knowledge gaps. These are key features of a well-conducted, systematised review as outlined by Grant and Booth (2009). The following provides a more specific account of the systematised review process used in this study.

Due to the diversity of terms used in the literature to define informal caregivers and the lack of a globally agreed definition of who constitutes a 'palliative patient', a comprehensive search strategy was carefully designed. This involved analysing a sample of Cochrane Reviews to identify relevant search terms. Consultation was then sought with CareSearch, a leading Australian palliative care knowledge network, to support the construction of a robust palliative search strategy consultation. This strategy was employed

to capture as much of the ill-defined and widely dispersed body of informal palliative caregiver literature as possible, knowing that the mindfulness search terms would reduce the number of citations and focus the search. A search strategy was formulated using a combination of controlled vocabulary and keywords, designed separately for each database searched (See Appendix 1). The targeted studies were primary peer-reviewed studies, reporting empirical data on the effects of mindfulness-based interventions for informal palliative caregivers. The search strategy was first employed in February 2014 to inform the research questions of this thesis and study design. Every 12 months the search was re-run to ensure an updated review of the literature. However, the establishment of alerts in each database enabled the identification of new studies as they were published. The following bibliographic databases were searched from their inception: Cochrane Library, CINHAL, MedLine, PsycINFO and EMBASE. No language restrictions or search limits were imposed.

CHAPTER 2:

INFORMAL PALLIATIVE CAREGIVING: A REVIEW OF THE LITERATURE

2.1 Chapter Introduction

This chapter provides an overview of the informal palliative caregiving literature. It is important to note, from the outset, that a research focus on informal palliative caregivers has lagged well behind patient-focused research in palliative care. To provide a coherent account of this diversely defined and dispersed body of research, the chapter is structured in three main parts. These parts reflect the literature's key domains of focus, including: (1) the role, profile and contribution of informal palliative caregivers, (2) the impact of end-of-life caregiving on the multidimensional realms of caregiver health and wellbeing, and (3) the range, feasibility and effectiveness of caregiver support interventions.

2.2 The Role, Profile and Contribution of Informal Palliative Caregivers

This section begins by defining what constitutes a palliative illness and outlining the available systems of care. A definition of informal palliative caregivers is then provided, followed by a description of the central role and contribution they make in providing end-of-life care.

2.2.1 Defining a Palliative Illness and Available Systems of Care

An individual with a 'palliative illness' can be defined as someone who has 'an active, progressive, advanced disease which has little or no prospect of cure and who is expected to die' as a direct consequence of this disease (Palliative Care Australia 2018a, p 5). This definition includes both malignant and non-malignant disease such as cancer, chronic

obstructive pulmonary disease (COPD), heart, liver or renal failure, motor neurone disease, dementia and Alzheimer's disease, Parkinson's Disease, Huntington's Disease, multiple sclerosis and HIV/AIDS (Palliative Care Australia 2018b; World Health Organisation 2019a).

People living with a palliative illness have complex, multifaceted needs in terms of pain and symptom management and physical, emotional, psychological, social, spiritual and practical support. Palliative care is a holistic care approach that aims not only to address these multifaceted patient needs to increase comfort and quality of life, but to include a focus on the assessment and care of family members, who are conceptualised as part of 'the unit of care' (Palliative Care Australia 2018b). Palliative care is defined in the Global Atlas of Palliative Care at the End of Life as:

> An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Palliative Care Alliance & World Health Organisation 2014, p 5).

Palliative care can be provided by a range of service providers. These can include both specialist and generalist palliative care providers, from multi-disciplines such as medical, nursing, social work, psychology, speech pathology, occupational therapy, pharmacy, physiotherapy, as well as support personnel, personal care assistants and volunteers. Palliative care has been most consistently regarded as an approach geared towards cancer-based illness (Currow, Abernethy & Fazekas 2004; Skilbeck & Payne 2005). The literature has found that patients with non-malignant diseases and their family carers have often failed to be recognised as being suitable for palliative care and have not been

referred to palliative care services until late in the disease trajectory, if at all (Gadoud & Johnson 2015; Ostgathe et al. 2011; Phillip et al. 2014). Studies have identified a range of adverse consequences of this missed opportunity for timely connection with palliative services, including poorer quality of life, greater distress, uncontrolled symptoms and burdensome or unwanted treatments at the end of life (Ferrell et al. 2017b).

Whilst people living with a palliative illness can be cared for across a range of settings, including hospitals, aged care and specialised hospice or palliative care units, palliative care provision at home is common (Leff et al. 2015, Palliative Care Australia 2012). The care provided in the homebased community setting is predominantly provided by family caregivers, supplemented and supported by the range of formal service providers previously described (Johnston and Milligan 2012; Sepulveda et al. 2002). Care at home often occurs due to a variety of factors. These include patient and family preference (Addington-Hall, Fakhoury & McCarthy 1998; Harding & Higginson 2003) and unfavourable care experiences in other settings (Linderholm & Friedrichsen 2010). A lack of alternative care options is also common, particularly in rural areas (Rainsford et al. 2017; Robinson, Pesut & Bottorff 2010), due to a deficit of hospice and acute-care beds to service an increasing number of people with palliative and supportive care needs (Aranda & Peerson 2001; Jansson, Dixon & Hatcher 2017). Additionally, the driving forces of economics have underpinned a significant shift in policy over recent years toward community-based palliative care (Zapart et al. 2007; Australian Institute of Health and Welfare 2017). For example, in 2014 the estimated cost of community care in the last year of life in Australia of $77 million is significantly less than the estimated $2.4 billion spent on delivering hospital and residential aged care services in the last year of life (Swerissen, Duckett & Farmer 2014).

2.2.2 Defining an Informal Palliative Caregiver

An 'informal palliative caregiver', as defined in this thesis, can be described as someone who provides for the practical, physical or emotional support needs of a significant other who is living with an incurable, life-limiting illness (Jaffray et al. 2016). The informal palliative caregiver role, undertaken from the basis of kinship or social connection in an unpaid capacity, should not be confused with that of professionals or volunteers who provide care as a function of working within a service (Candy et al. 2011). These people share the illness experience with the patient and provide direct care and emotional support as part of a relational dynamic (National Institute for Health and Care Excellence (NICE), 2004). Other terms in the literature used to describe informal palliative caregivers have included 'family caregivers', (Emmanuel et al. 2000; Hudson, Aranda & Kristjanson 2004) 'home carers', (Parker, Arksey & Harden 2010) and 'lay carers' (Donnelly, Michael & Donnelly 2006; Healy et al. 2018). The terms 'spouse', 'partner' or 'families' (Given et al. 2004) are also used, as these people frequently take on caregiving roles. Surprisingly, many studies have provided limited detail when describing their caregiver populations. For example, a systematic review of the published caregiver literature (1998-2008) by Stajduhar et al. (2010) found that two thirds of reviewed studies (n=129) did not define who they meant by informal caregivers. The diverse and often ill-defined terms ascribed to informal palliative caregivers, in both the published and grey literature make it difficult to identify all relevant caregiving research and to synthesise findings across studies.

In addition to the diverse terminology used by others to define informal palliative caregivers, caregivers themselves hold diverse conceptualisations of their role. The literature has shown many participants in caregiver research do not self-identify or see

themselves as ‘a carer’ (Grande et al. 2009; Henderson 2001; McDougall, O’Connor & Howell 2018; Molyneaux et al. 2011; O’Connor 2007). For example, one telephone interview study of older adults (n= 4037) in the United States found that 44% of people who, based on their caregiver activities could be assessed as ‘a carer’, did not identify with the term (Kutner 2001). An increasing number of studies have discovered that people are more likely to conceptualise their caring role as a natural extension of their existing relationships. For example, they consider themselves as a spouse, child or parent, as opposed to seeing themselves as ‘a caregiver’ in a distinctively different role (Gardiner et al. 2016; Grande et al. 2009; Harding & Higginson 2001). The need for caregivers to access and engage with support services has been found to prompt a reconceptualization of their role (Molyneaux et al. 2011). One qualitative study of family caregivers in Canada (n=47) found that it wasn’t until after interactions with health providers that caregivers identified with the term ‘carer’. The authors concluded that caregiver identity was highly influenced by and ‘produced primarily through interactions with others’ (O’Connor 2007, p 165), particularly those in formal systems of care.

Contentions and debates about the usefulness of the term ‘carer’ further permeate the literature (Phillips 2007). Whilst the term ‘carer’ is acknowledged for having made visible the value of ‘care work’ and to leverage greater support and access to services, it has been perceived to imply burden. Further, this has been regarded to polarise the ‘carer’ and the person being cared for, rather than bringing individuals together to navigate a shared experience (Keith 1992; Molyneaux et al. 2011). Additionally, the term ‘carer’ has been regarded to have created an ambivalent space for family members caring for a significant other at the end of life (Stajduhar et al. 2008b). For example, caregivers have been perceived to occupy dual roles as both providers and recipients of care (Grande et al. 2009;

Harding & Higginson 2001). They both work alongside services to provide care, but due to the demands and adverse impacts of caregiving are also legitimate service users themselves. For this reason, they have been described within the literature as 'pseudo-patients' (Kristjanson et al. 1996) or 'hidden patients' (Kristjanson & Aoun 2004, p 359) with their own needs.

The literature reveals that an added complexity in defining informal caregivers is further tied to the way in which people often come to the caregiver role. For example, studies have found that for many caregivers there is no set start point of becoming a caregiver, but rather more of a 'falling into' or 'morphing' into the role (Aranda & Peerson 2001; Girgis et al. 2013a). This means that people can be functioning in a caregiving role without having been conscious of or identifying with it. For example, Phillip et al. (2014) interviewed 14 current and bereaved caregivers of patients with Chronic Obstructive Pulmonary Disease (COPD) in Australia and found that the care recipient's progressive disability and greater care needs resulted in them 'doing more over time' and unconsciously assuming a caregiver role. Other studies have identified that caregivers take up the 'carer' role by default, due to others 'just assuming' they would become the caregiver (Linderholm & Friedrichsen 2010) or because of a lack of alternative care options (Funk et al. 2010).

The complexities surrounding both the language assigned to describe caregivers and the different ways that people navigate into the role of providing informal palliative care are important to note. For whilst we need labels and terms to identify and describe people who are in the caregiving role, there is a tension between the language applied within the literature and the way caregivers identify themselves. The limitations, diverse conceptualisations and variable identification with the term are recognised in this study. In

the absence of another consistently regarded and applied descriptor, the term 'informal palliative caregivers' will be used within this thesis, also referred to at different times more succinctly as 'caregivers'.

2.2.3 The Prevalence and Profile of Informal Palliative Caregiving

According to the World Health Organisation (2018), research into palliative care at the end of life, globally around 40 million people each year require palliative and supportive care. This is expected to increase significantly over coming decades due to increased life expectancy and associated disease burden (Etkind et al. 2017; Ferlay et al. 2013; Gomes & Higginson 2008; Gómez-Batiste et al. 2014). In Australia, there is a lack of comprehensive, publicly available palliative care data, both regarding the number of people who are receiving palliative care, as well as the number of informal palliative caregivers (Palliative Care Australia 2018b). What is known, is that 160,000 people die each year in Australia (Australian Bureau of Statistics 2017) with the largest percentage of those deaths resulting from a palliative illness. For example, in 2018, the top five underlying causes of death for males and females of all ages combined, included coronary heart disease, dementia and Alzheimer's disease, cerebrovascular disease (including stroke), lung cancer and chronic obstructive pulmonary disease (Australian Institute of Health and Welfare 2018). We also know that many people with a palliative illness are supported by a family caregiver (Palliative Care Australia 2012) and that their contribution to patient care is substantial (Johnston et al. 2012; O'Connor et al. 2009). For example, in a longitudinal study of the impact of advanced cancer on patients and their informal caregivers (n=200) in the United States, two thirds of caregivers self-reported undertaking between 80-100% of patient care

(Vanderwerker et al. 2005). The prevalence and contribution of informal palliative caregivers to end-of-life care is starkly highlighted by Palliative Care Australia (2012, p 139):

> Regardless of the place of death, it is estimated that up to 90% of people in the terminal phase of a life-threatening illness spend the majority of their time at home supported by a carer.

A report commissioned by Carers Australia on the economic value of informal carers in Australia, including but not restricted to palliative care, estimated that there were 2.86 million informal carers in Australia in 2015 (Deloitte Access Economics 2015). Whilst informal caregiving is undertaken by diverse people of different ages, in different relationships and contexts, the report identified that most Australian caregivers are female, 45-years or older, caring for a spouse or partner and living with the care recipient. Additionally, informal caregivers were found to be slightly more likely to live outside metropolitan areas in Australia, compared to non-carers (Deloitte Access Economics 2015). Underlying factors may include difficulties accessing services in rural and remote settings and a subsequent greater reliance on informal networks for care and higher rates of poor health compared to metropolitan areas, particularly among men (Australian Institute of Health and Welfare 2017).

2.2.4 The Provision of Informal Care

Informal palliative caregivers provide a critical role in supporting the multidimensional needs of a family member or friend with a palliative illness. Research has consistently identified the availability and willingness of informal caregivers to provide care are critical factors underlying the possibility of palliative care at home (Alonso-Babarro et al. 2011; Gomes & Higginson 2006; Linderholm & Friedrichsen 2010; Martin, Olano-lizarraga &

Saracíbar-razquin 2016) and also death at home if this is the patient and family preference (Grande & Ewing 2008; Harding et al. 2012).

Caring for a significant other at the end of life and their rapidly changing needs involves undertaking a range of multifaceted, unfamiliar tasks, often whilst still coming to terms with a terminal diagnosis (Funk et al. 2010; Girgis et al. 2006). These tasks are often broadly categorised in the literature as personal care, household care and management care (Visser et al. 2004). Personal care involves assistance with activities of daily living such as washing, dressing and assisted mobility. It also relates to medication management, which has been found to invoke concerns amongst caregivers about over or under-dosing of the care recipient (Kazanowski 2005; Lau et al. 2009). Household care includes cooking, shopping, cleaning and running errands. In a national survey study of 1149 informal caregivers in the United States, caregivers reported undertaking 85% of the shopping and transport and 83% of household tasks (Wolff et al. 2007). Management care activities can include advocacy, facilitating engagement with diverse health systems, managing finances, legal issues, aiding decision making and advance care planning (Visser et al. 2004).

The intensity of these caregiving responsibilities has been unsurprisingly found to increase as the care recipient becomes increasing unwell (Matthews 2018; McCorkle & Pasacreta 2001; O`Hara et al. 2010). Depending on illness trajectory and disease progression, mastering these roles and challenges may need to occur in an intense, but limited period, which may result in carers feeling unprepared, overwhelmed and unsure of their role (Andershed 2006; Angelo & Egan 2015; Linderholm & Friedrichsen 2010; Tang 2009). Alternatively, these roles may need to be provided for a protracted length of time as is often the case with non-malignant diseases such as dementia (Haley 2001).

Beyond the unquantifiable value to the person for whom they are caring, informal caregivers also constitute a significant economic resource for governments around the world (Gardiner, Ryan & Gott 2018; Round, Jones & Morris 2015). A 2015 study in the United Kingdom estimated the direct and indirect costs of care at the end of life for patients across four cancer diagnosis groups of lung, breast, colorectal and prostate cancer to be £641 million; (over one billion Australian dollars). The value of informal caregiving accounted for approximately one third of these costs (Round, Jones & Morris 2015, p 902). In Australia, informal caregivers are similarly a critical health-care resource, outnumbering formal paid care providers five-to-one (Australian Institute of Health and Welfare 2003). In a 2015 report prepared for Carers Australia, informal caregivers were estimated to provide 1.9 billion hours of care in Australia, which, if required to be replaced by health services, would be a cost of $60.3 billion (Deloitte Access Economics 2015, p 3). Caregiving will continue to be important in Australia as the population ages. Informal caregiving resources are likely to be impacted by projected demographic trends, including increased female workplace participation and longer years of workforce participation in general, smaller and more geographically dispersed families and increased rates of relationship breakdown (Mariotto et al. 2011; Miller et al. 2016).

Informal palliative caregivers, whilst diversely defined are clearly critical to the provision of end-of-life care, particularly in the home setting. Undertaking intense, multifaceted care work, informal caregivers work alongside a range of health professionals to maximise the quality of life and to attend to the holistic needs of their significant other. In the absence of informal caregivers, there is a significant risk of services being overwhelmed and unable to provide quality palliative care and a clear implication for health-care expenditure. Investment in the development of strategies and resources to support informal

caregivers to undertake their vital care work is imperative (Grande et al. 2009; Hudson, Zordan & Trauer 2011; Larkin et al. 2016; Williams, Wang, & Kitchen 2016).

2.3 Exploring Impacts of Informal Palliative Caregiving

A significant amount of the informal palliative care literature consists of studies examining the impact of providing end-of-life care. This section presents what is known from the published literature in terms of the adverse and positive impacts of end-of-life caregiving across the multiple domains of caregiver health and wellbeing. Factors influencing caregiving impact are discussed, along with several conceptual models explaining the variations in caregiving outcomes.

2.3.1 Adverse Impacts of Informal Caregiving

It is well-documented that providing care to a family member or friend with a palliative illness can place significant stress on a caregiver's personal resources. A range of adverse effects on caregiver health and wellbeing across the physical, emotional, psychological, social and financial domains have been identified in the literature. These adverse effects have been found to compound over the disease course (Dumont et al. 2006; Grant et al. 2013; Grunfeld et al. 2004; Wilkinson 2010) and can extend to bereavement (Ferrario et al. 2004; Williams & McCorkle 2011). Caregiver burden is a term frequently used in the literature to describe the collective stressors and negative physical, mental, emotional, social and economic consequences of providing care (Williams et al. 2013). Many definitions of caregiver burden emphasise an imbalance between the demands of caregiving and available resources to meet those demands (Applebaum, Kulikowski & Breitbart 2015; Given, Given & Kozachik 2001). For the purposes of examining the adverse impacts of

caregiving on caregiver health and wellbeing in this thesis, the domains of impact (physical, psychological, emotional, social, spiritual, financial) have been separated and will now each be discussed in turn. However, this is not without recognition that there is great overlap and interconnection between these domains.

Physical Impacts

The adverse physical effects of caregiving have been observed across a range of studies (Aoun et al. 2005a; Grande et al. 2009; Grbich, Maddocks & Parker 2001b; Stajduhar et al. 2010). Increased risk of serious illness (Shaw et al. 1997), as well as increased caregiver morbidity, have been identified in several caregiver studies (Schulz & Beach 1999; Shulz et al. 2004; Schulz & Sherwood 2008). Strikingly, Schulz and Beach's seminal 1999 study of 392 informal caregivers aged 66 years and older found a 63% higher mortality risk in caregivers compared to non-caregiver controls. Caregivers have also been shown to experience an exacerbation of chronic health conditions or physical symptoms such as blood pressure, back pain and heart palpitations (Northouse et al. 2012; Waldrop 2007). However, caregivers typically delay attending to their own physical illness or ailments to focus on the care recipient (Coristine et al. 2003; Stajduhar 2013). For example, Burridge et al. (2011) in an Australian qualitative study of advanced cancer caregivers (n=6) and health professionals (n=19), identified that caregivers prioritised attending to patient needs over their own, even when their own physical health ailments were pressing. Caregivers have also reported increased physical demands that accompany personal care and assuming labour roles previously performed by the person being cared for, such as gardening and house maintenance (Angelo & Egan 2015). High levels of fatigue have also been reported amongst caregivers (Funk et al. 2010; Grbich, Maddocks & Parker 2001b; Harding et al. 2012a). This

fatigue is often the result of several associated factors such as prolonged stress (Martin, Olano-lizarraga & Saracíbar-razquin 2016; Waldrop 2007), disturbed and inadequate sleep at night (Carter 2006) and inability to rest during the day due to caregiving demands (Carter & Chang 2000).

Psychological and emotional impacts

Adverse effects on psychological health resulting from caregiving are also well established in the literature, particularly increased rates of depression and anxiety (Burridge, Barnett & Clavarino 2009; Fletcher et al. 2008; Given et al. 2004; Grunfeld et al. 2004; Hauser & Kramer 2004; Kurtz et al. 2005; Rhee et al. 2008; Shulz & Menderlsohn et al. 2003). Rates of caregiver depression and anxiety have been variously reported across different studies of caregiver populations, ranging from 12-59% and 30 -50% respectively (Grunfield et al. 2004; Hauser & Kramer 2004; Hudson & Payne 2011; Hudson et al. 2015) and in many studies exceed patient rates of depression and anxiety (Aranda & Hayman-White 2001; Given, Given & Kozachik 2001; Mikulincer, Rydall & WaBraun 2007).

Caregivers experience high rates of psychological distress and have lower levels of mental health compared to the general population (Payne, Smith & Dean et al. 1999). The disparity between the psychological and physical health status of caregivers compared with non-caregivers was starkly highlighted by a meta-analysis by Pinquart & Sörensen (2003). Their analysis of 84 studies established that, compared to non-caregiver populations, caregivers experienced significantly lower levels of subjective wellbeing, physical health and self-efficacy and higher levels of stress and depression. An Australian study by Zapart et al. (2007) of informal palliative caregivers (n=82), caring for patients (most commonly with metastatic cancer receiving community palliative care services) discovered that carers had

substantially lower mental health scores compared to that of the Australian population. Studies have also reported that caregivers experience high levels of helplessness and distress, but frequently 'submerge these intense responses while caregiving' (Waldrop 2007, p 202). Underlying reasons for this 'submergence' have been identified as a desire to both protect and not divert attention away from the care recipient and their needs. A phenomenological study of 10 informal palliative caregivers in Canada, found that increased levels of helplessness amongst caregivers acted as a trigger for the admission of care recipients to palliative care units (Perrault, Fothergill-Bourbonnais & Fiset 2004). Other studies (Stajduhar et al. 2008a; Topf, Robinson, Bottorff 2013), have also drawn links between feelings of helplessness amongst caregivers and ensuing difficulty in sustaining care at home.

Several emotional impacts of providing end-of-life care are also identified in the literature. A prominent theme is the experience of distress amongst caregivers watching those they care for become increasingly frail (Angelo & Egan 2015; Harding et al. 2012a; Waldrop 2007). A qualitative study of 12 caregivers caring for a family member or friend with advanced breast cancer in Canada described this as 'witnessing diminishment' (Sinding 2003, p 161). Caregivers also report experiencing heightened vulnerability and uncertainty, (Grbich, Parker & Maddocks 2001a; Harding et al. 2012a) as well as being unprepared for and fearful of the impending death of their significant other (Andershed 2006; Breen et al. 2018). Despite the sense of distress, fear and uncertainty identified in the literature, caregivers commonly report a perceived need to maintain a positive, emotional front or 'self-control' (Oyebode, Smith & Morrison 2013), underscored by a desire to protect the care recipient or project an impression of strength and dependability (Linderholm & Friedrichsen 2010). Martin, Olano-lizarraga and Saracíbar-razquin (2016) argued that this

can have an effect of emotionally isolating the caregiver from the person for whom they are caring, resulting in adoption of avoidance-based responses to difficult feelings and concerns.

The literature on adverse impacts of providing care on informal palliative caregivers also illuminates the further effect of multiple, intense experiences of grief and loss on caregiver health and wellbeing. This includes both during caregiving in the form of daily incremental and anticipated loss, as well as in bereavement, post the death of their significant other (Thomas et al. 2014). Grief as described by Waldrop (2007, p 198) 'is the multifaceted response to death and loss of all kinds, including emotional (affective), psychological (cognitive and behavioural), social and physical reactions'. These multidimensional reactions documented in the literature include, but are not limited to, intense feelings of sadness, anger and despair, behaviours such as agitation, social withdrawal, avoidance of difficult experiences, cognitive effects such as preoccupied thinking, difficulty concentrating, depression, and physical symptoms such as fatigue and increased physiological stress responses (Breen & O'Connor 2007; Stroebe, Schut & Stroebe 2007). These reactions are often experienced as unfamiliar and overwhelming by caregivers which can add to feelings of vulnerability and helplessness (Davis, Deane & Lyons 2016). A number of authors have found this to be particularly common amongst caregivers in the absence of 1) information that normalises these intense responses; 2) the provision of support to help caregivers find their own way of adjusting to and managing their grief; or 3) referral to appropriate psychological services and resources where indicated (Aoun et al. 2015b; Waldrop 2007; Waller et al. 2016). Ironically, experiencing the full impact of grief and loss, post the death of their significant other often coincides with the withdrawal of services and other supports that were present during caregiving (Götze et al. 2018; Harrop et al. 2016). Other research (Sinding 2003; Totman et al. 2015; Wong & Ussher 2009) has

shown that in bereavement, caregiver reflection on their role and the self-judgements they make about whether they did 'the right thing' or 'enough' for their significant other, has the potential to have emotional and psychological impacts. For example, feelings of guilt and other negative effects of this self-evaluation have been identified when caregivers perceive a disconnect between the care they wanted to provide against what they were able to provide (Harrop et al. 2016; Sinding 2003; Totman et al. 2015).

Caregivers frequently cite unmet needs for emotional and psychological support (Andershed 2006; Cain, MacLean & Sellick 2004; Hudson 2006; Morris et al. 2015; Linderholm & Friedrichsen 2010; Proot et al. 2003; Rolinson & Carlsson 2002). A number of studies have revealed that caregivers experience a sense of being invisible (Brobäck & Berterö 2003, Martin, Olano-Lizarraga & Saracibar-Razquin 2016), being 'in the shadows' (Linderholm & Friedrichson 2010) or 'caring in the dark' (Andershed & Ternestedt 2001). A qualitative study, of 14 family caregivers of palliative patients in Sweden, found that caregivers had a need 'to be seen' or for care professionals to empathically inquire about and listen to their experience, challenges and needs (Linderholm & Friedrichsen 2010). Other studies have pointed to the need for caregivers to be encouraged to access psychosocial support and to see this as a legitimate resource. For example, Hudson and Aranda (2014) explains that many caregivers are interested in strategies to support their psychological health but are reluctant to ask for this support without being prompted or supported to do so. A study exploring the experience of caregiver burden and use of psychological services in a population of 25 caregivers of terminal cancer patients in the United States discovered that 64% of caregivers were not accessing any therapy or counselling, yet 92% of these same caregivers reported interest in receiving services (Applebaum, Kulikowski & Breitbart 2015).

However, this sample was drawn from caregivers of patients who were accessing psychiatric help and may not be generalisable to other informal palliative caregivers.

Social impacts

The impact of caregiving is also reported in the literature to affect many social domains and relationships (van Roij et al. 2018). Social isolation, is commonly reported by caregivers, caused largely by the demands and responsibilities of providing care taking priority (Balfe et al. 2017). Leisure, social activities and networks that may have once provided social connection are often reframed by caregivers as self-indulgent or no longer appropriate to pursue in the heavy presence of a palliative illness (Girgis et al. 2013b; McDougall, O'Connor & Howell 2018). These activities and connections are often forgone to fully focus on the care recipient's needs (Boyd et al. 2004; Cain, MacLean & Sellick 2004; Stajduhar 2013; Strang & Koop 2003). Qualitative research has played a particularly important contribution in understanding these wider impacts of caregiving, rather than the variables more commonly focused on in quantitative studies. For example, qualitative studies of caregivers have found they commonly feel distanced from others due to the social taboos and discomforts raised by and surrounding grief, death and dying (Ewing et al. 2016a). Caregivers are often reluctant to engage with or disclose their experience to others who they perceive cannot truly appreciate what they are going through (Cain, MacLean and Sellick 2004; Holtslander et al. 2017). Steiner (2006) reports that in other instances, people will distance themselves from caregivers and the person they are caring for because of their own sense of uncertainty and discomfort with death and dying. This withdrawal can also occur post-death and in bereavement, compounding a caregiver's experience of social isolation at the very time that support is often most needed.

A range of qualitative studies have reported that changing relationship dynamics between the caregiver and the person being cared for, can be another source of social isolation and stress. As the care recipient becomes more dependent on the caregiver for care, there is a shift in long established roles and ways of connecting and a resultant loss of reciprocity in the relationship (McConigley et al. 2010; Ray & Street 2007; Thomas, Morris & Harman 2002). This has been found to involve a 'redefining of the relationship' (Martin, Olano-lizarraga & Saracíbar-razquin 2016, p 7) to accommodate very changed circumstances and the reprioritising of needs. An example lies in changed communication, from one of openly sharing experiences and expressing needs in a relationship of equals, to a more guarded approach as the care recipient becomes increasingly unwell (Martin, Olano-lizarraga & Saracíbar-razquin 2016; McConigley et al. 2010).

Having to negotiate acceptance of formal services with the care recipient has also been found to strain relationships as care recipients often initially refuse formal services, perceiving them as unwanted intrusions (Cain, MacLean & Sellick 2004; Funk et al. 2010). Respecting care recipients' needs, and positions can place tension on the ability of caregivers to secure the support they need to sustain care. Waldrop (2007) found that the reprioritising of focus on care-recipients' needs has also been found to have a systemic effect of 'loss', with regards to other relationships:

> Caregiving for someone who is dying becomes the primary focus and changes the nature of all social relationships. These accompanying social losses ripple through the network of family members, friends, neighbours, acquaintances and co-workers (p 203).

In addition, the emotional, practical, financial strains of end of life experiences can also create tension and conflict within family relationships and networks. Caregivers have reported experiencing stress from trying to secure and negotiate help from family members (Angelo & Egan 2015), to manage fractured family relationships and when dealing with family conflict (Grbich, Maddocks & Parker 2001b).

Financial impacts

Financial strain and pressures associated with end-of-life caregiving, recently coined 'financial toxicity' (Chi 2017; Paul et al. 2017), have also been documented in the caregiver literature (Gardiner, McDermott & Hulme 2017; Gott et al. 2015; Palliative Care Australia 2017). This is most often reported when caregivers encounter limits to or have to forgo paid employment altogether to provide care (Rossi et al. 2007; Hebert & Schulz 2006; Martin, Olano-lizarraga & Saracíbar-razquin 2016; Stajduhar et al. 2010). In 2015, a nationwide survey of disability, ageing and carers in Australia, including informal palliative caregivers, reported that only 56.3% of primary carers were engaged in the workforce, compared to 80.3% of non-carers and had a 42% lower weekly median income than non-carers (Australian Bureau of Statistics 2016). Additional expenses such as medications, treatments, equipment hire or purchases, transport to health appointments and payment for services have been shown to increase the financial impact of informal palliative caregiving (Gardiner, McDermott, Hulme 2017). Other research identified that caregivers have to negotiate financial resources from government and private agencies (Cain, MacLean & Sellick 2004) and contend with a range of legislation such as taxation, superannuation and employment policies, that often fail to fully consider the complexity of caregivers' situations (Kirby et al.

2018). The inflexible bureaucracy of such policies has been regarded to increase financial strain and contribute towards the marginalisation of caregivers (Aoun et al. 2005a).

This section has summarised the breadth of literature on the adverse impacts of caregiving with a focus on the following domains: physical, psychological, emotional, social, and financial. To date, there has been a large and predominant research focus on exploring the 'burden' and negative effects of caregiving (Girgis et al. 2013b). This is perhaps influenced predominantly by the disease and deficit focused lenses of the psychological and medicine-based paradigms, that are most prevalently applied in caregiver research. The next section will present what is known in the literature about the more positive aspects of caregiving.

2.3.2 Positive Impacts of Informal Caregiving

In comparison to studies exploring the adverse aspects of caregiving, it is striking how few studies have sought to understand and report the positive experiences and impacts of end of life informal caregiving (Carlander et al. 2010; Henrickson et al. 2013). Hudson poignantly points out, that by focusing only on the negative effects of caregiving, 'there is a danger in pathologising caregiving and inadvertently socialising caregivers to expect burden' (2003a, p 359). A small number of studies have identified that caring for a family member or friend with a progressive, incurable disease can also involve positive, rewarding and transformational experiences (Hudson et al. 2004; Jo et al. 2007). Frequently, these positive aspects of caregiving are spoken about as offering the potential to buffer against the adverse effects outlined in the previous section (Applebaum, Kulikowski & Breitbart 2015; Folkman 1997).

Strengthened relationships and increased closeness between the carer and the care-recipient are one of the more positive aspects of end-of-life caregiving identified in the literature (Applebaum, Kulikowski & Breitbart 2015; Hudson 2004; Jo & Brazil 2007; Linderholm & Friedrichsen 2010). Other research has identified that positive impacts of the caregiving role can include: feeling a sense of achievement (Andershed 2006; Stajduhar & Davies 2005; Zapart et al. 2007) or 'feeling proud' to have managed care (Linderholm & Friedrichsen 2010; Grbich, Parker and Maddocks 2001a), discovering personal resourcefulness or strength (Jo et al. 2007; Waldrop et al. 2005), and gaining enhanced 'self-knowledge' (Henrickson & Arestedt 2013a; Oldham & Kristjanson 2004; Stajduhar 2003; Wolff et al. 2007). Finding a sense of meaning is another commonly reported positive aspect of caregiving elucidated in the qualitative literature (Milberg & Strang 2003; Waldrop 2007; Applebaum, Kulikowski & Breitbart 2015). A small number of studies (Grbich, Parker & Maddocks 2001a; Stajduhar & Davies 1998; Zapart et al. 2007) have detailed how caregivers ascribe meaning to the act of providing care as 'giving-back-to' or repaying kindness that the care-recipient has provided during their life journey together. Caregiving has been further described as 'a privilege' (Breen et al. 2018). These findings suggest the potential for caregiving to bring about positive, transformational effects on the way in which caregivers come to understand and experience themselves, their abilities and their relationships (Waldrop et al. 2005). Some authors go as far as identifying post traumatic growth as a positive outcome of caregiving (Hudson et al. 2006; Pinquart & Sörensen 2003a).

2.3.3 Mediating Factors of Caregiver Outcomes

The literature details that informal palliative caregivers experience the impacts of caregiving (positive and negative), in diverse ways and can have variable outcomes

(Braithwaite 2000; Cooper, Kinsella & Picton 2006; Lawton et al. 1991). Determining the variables that enhance or detract from a positive caregiving experience is essential in the design and implementation of interventions for caregivers in the palliative context and remains an area for further research (Grov et al. 2006; Stajduhar et al. 2010). Potential variables are broadly categorised in the literature as being related to three key areas: 1) access to informal and formal resources and support, 2) patient clinical characteristics, including care requirements and 3) caregiver characteristics and appraisals.

Access to both informal and formal resources and support has been found to influence more positive caregiver outcomes. Perceived adequacy of informal support, which involves social connection, emotional support and practical based support from friends and family (Bloom 2000) has been found to contribute towards caregivers feeling more resourced to manage their caregiving role (Perrault, Fothergill-Bourbonnais & Fiset 2004; Cooper Kinsella & Picton 2006; Martin, Olano-lizarraga & Saracíbar-razquin 2016). A relationship has also been found between informal or social support and caregiver quality of life (Lim & Zebrack 2004; Nijober et al. 1999a) and psychological and physical adjustment (Kinsella et al. 2000). Authors such as Rosenberg et al. (2015) suggest that the role and value of informal support networks has been a largely neglected area of research.

Regarding formal services, the provision of timely and adequate information and support has been found to support more positive caregiver outcomes. These include increased preparedness to care and a sense of security (Hudson 2003a; Stajduhar et al. 2008a; Stajduhar et al. 2010), decreased caregiver stress and anxiety (Hudson 2003a) to buffer against care-recipient admission to acute care and adverse caregiver outcomes in bereavement (Aoun et al. 2018a). In a large matched cohort study of more than 30,000

patient and spousal carers in the United States utilising hospice services for terminal care, compared to a sample who didn't, Christakis and Iwashyna (2003) found the provision of terminal care by hospice services reduced the likelihood of caregivers becoming ill or dying in bereavement.

The second set of influences on caregiver outcomes identified in the literature relates to patient clinical characteristics and care requirements (Stajduhar et al. 2010) although, findings again are mixed. Lower patient performance or functional status is associated with increased distress amongst caregivers (Cameron et al. 2002; Dumont et al. 2006; Grunfeld et al. 2004), but not so in others (Given et al. 2004). There is some evidence that lower patient health and functional status results in lower caregiver quality of life (Weitzner & McMillan 1999) and greater caregiver burden (Grunfeld et al. 2004). However, a longitudinal study by Nijboer et al (1999b) found no relationship between caregiver quality of life and the care intensity or patient dependency in activities of daily living. Relationship factors are also relevant. For example, in a study of 101 patients with advanced gastrointestinal or lung cancer and their spouse caregivers, relational variables including marital dissatisfaction and attachment orientations were important predictors of caregiver depression (Braun et al. 2007).

Caregiver characteristics and appraisal of stress and self-efficacy constitutes the third type of mediating factor on caregiver outcomes explored in the literature. The evidence for caregiver age and gender influencing caregiver outcomes such as distress, caregiver burden and depression are similarly very mixed (Dumont et al. 2006; Hudson 2003a; Lim & Zebrack 2004). The influences of caregiver education and socioeconomic status are not clear (Cameron et al. 2002). Caregiver appraisal of stressors in terms of perceived threat to

coping, has been found to be more determining of caregiver outcomes than access to resources and patient clinical characteristics and care requirements (Aranda & Hayman-White 2001; Cameron et al. 2002; Yates et al. 1999). Hudson (2003a, p 354) explains:

> It is the subjective understanding of events and not their objective features that best determine stress. Therefore, the reaction to the stressful event does not rely solely on the demands of the situation or on the resources available to the person, but on the relationship between the demands and resources as perceived by the person.

2.3.4 Models Explaining Caregiver Outcomes

Several models have been used in palliative caregiver research to explain variances between the impact of stress on different individuals. These models most notably include the larger sociological frameworks and theories of Lazarus and Folkman's Transactional Model of Stress and Coping (1984) and Perlin's Stress Process Model (1990). A review of these models is beyond the scope of this thesis. Suffice to say, these models have provided a helpful lens through which to examine the mediating factors of caregiver outcomes in the setting of palliative care. For example, Hudson (2003a) developed a modified Transactional Stress and Coping Framework, based on the work of Lazarus and Folkman (1984) and Folkman (1997). In doing so, Hudson (2003) provided a conceptualisation of family caregiver response to supporting a family member at the end of life. This model emphasised subjective caregiver appraisal of their self-efficacy to meet the demanding events in caregiving and coping strategies, as opposed to the event in and of itself, as the most powerful predictor of caregiver stress. Waldrop et al. (2005) utilised Perlin's Stress Process Model to explain the caregiving experience of 74 American family carers of hospice patients. Through qualitative interviews, Waldrop et al. (2005, p 632) identified that caregiver

perception of the availability and effectiveness of resources, specifically, social support and religious or faith practices, mediated decreased negative indicators of emotional and psychological distress and increased positive meaning making.

Other models have moved beyond these frameworks to elucidate the influencing factors of adaption to stressful caregiving events and milestones. For example, Duggleby and colleagues (2017) proposed a conceptual framework of 'redefining normal' to describe the adaptive processes associated with managing critical transitions in end-of-life caregiving. Other models such as the model proposed by Proot et al. (2003), have provided additional value by identifying the oscillating nature of coping and adapting to stressors, rather than it being a fixed experience.

A number of authors have criticised the lack of attention in conceptual models to the cultural factors and dominant narratives or ideals around caregiving and their impact on caregiver outcomes (Brazil et al. 2003; Carlander et al. 2010; Kinsella et al. 2000; Hudson 2003a; Pasacreta & McCorkle 2000). For example, Stajduhar et al. (2010, p 586), in their review of the informal palliative caregiver literature, state:

> Existing conceptual models tend to be psychological and focused on individual characteristics (e.g patient and caregiver); caregiving stressors (e.g patient symptoms) and caregiver coping and appraisal to explain caregiver outcomes…a multilevel understanding of contextual influences on outcomes for family members providing palliative care is lacking.

To summarise this section, whilst a small number of studies have identified positive aspects of caring for a family member or friend with a palliative illness, the literature has predominantly focused on adverse effects. A range of mediating factors on caregiver

outcomes have been identified, with the perceived availability of support (both formal and informal) identified as a key mediating factor. However, greater evidence for caregiver appraisal and perceived self-efficacy is noted. Closer attention is warranted to the broader cultural and contextual influences on the end-of-life caregiving experience and sense of coping. The critical point is that caregivers should be supported to manage the negative impacts of caregiving, as well as to enhance the opportunity to experience positive aspects of their role. Supportive caregiver interventions are the primary focus of the next section in this chapter.

2.4 Informal Palliative Caregiver Support Interventions

The provision of effective, evidenced-based informal caregiver support is an imperative consistently advocated by the World Health Organisation (2019a) and embedded in palliative care guidelines around the world (National Institute for Clinical Excellence 2004), including Australia (Palliative Care Australia 2018b). However, the operationalisation of this goal remains a challenge. The predominant focus of the informal palliative caregiver literature has been descriptive research, concerned with exploring the impact of caregiving. As a result, we know a lot less about the effectiveness of interventions for whom, in what format, when, how much or why.

This section will provide an overview of the most commonly employed and evaluated psychosocial interventions for informal palliative caregivers published in the peer review literature. Specifically, it will enable an understanding of the volume, focus and type of caregiver interventions trialled and findings of effect. Methodological limitations of reviewed studies and significant gaps in the existing body of research will be identified. A

critical understanding of the literature and its silences is fundamental to appreciating the focus, design and undertaking of the present study.

2.4.1 Approach to Reviewing the Intervention Research

The informal palliative caregiver intervention research is summarised in a significant number of overlapping systematic and narrative reviews. This section begins by presenting some of the key published reviews, most frequently cited in the literature to provide an overview of the field of intervention research in the context of end-of-life caregiving. These reviews have taken a broad focus in terms of reviewing a range of different intervention types. The second part of this section presents the findings of reviews which have taken a more specific focus: evaluating the evidence for each type of intervention.

In one of the earliest systematic reviews of informal palliative caregiver interventions, Harding and Higginson et al. (2003) identified only 22 intervention studies published between 1966 and 2001. Most of the interventions targeted patient need, with only nine exclusively focused on and delivered to caregivers. This review starkly illustrated the disconnect between the well documented negative effects of caring and the limited number of evaluated interventions: so much distress, so few interventions. Intervention types included respite, educational and problem-solving interventions, one-to-one therapy and group work approaches. The range of interventions was judged by Harding and Higginson (2003) as largely focused on supporting patient needs and narrow in terms of the diverse and complex needs of caregivers themselves. The authors concluded that there was some evidence of effectiveness for all the caregiver interventions reviewed. However, studies included small, convenience-based samples and were assessed as moderate to weak

in rigour, indicating a pressing need for rigorous and high-quality caregiver intervention studies.

An updated review by Harding and colleagues (2012b), identified an additional 33 published intervention studies in the proceeding decade, between 2001-2010. They reported an increase in both the number and quality of intervention studies for informal palliative caregivers (Harding et al. 2012b). Interventions were described as: group-based (n=10), psychological (n=8), palliative care and hospice interventions (n=6), psychological interventions for patient carer dyads (n=4), informational training interventions (n=3), respite (n=1) or yoga-based interventions (n=1). While the volume of interventions had increased, the authors found that small sample sizes and study heterogeneity made it difficult to synthesis findings about effectiveness and that there were mixed results across studies. Further, the authors remained critical of the narrow range of models 'in relation to caregivers' needs and preferences' (Harding et al. 2012b, p 7).

Another key review, published at a similar time, provided a meta-analysis of randomised controlled trials investigating supportive interventions for family caregivers of terminally ill patients, (Candy et al. 2011). The systematic review identified only 11 RCTs, reporting outcomes for 1836 informal palliative caregivers, most of whom were caring for significant others with metastatic cancer. Nine of the interventions were delivered directly to the caregiver, with two studies delivering caregiver support indirectly through patient intervention. Most interventions incorporated psychological and emotional support and information on managing care. The review concluded that there was low quality evidence that direct caregiver support interventions could reduce psychological distress in the short term, although effect sizes were small (Candy et al. 2011). The authors noted however, that

determining the risk of bias was problematic due to the under-reported methods in many of the reviewed studies.

More recent review studies have demonstrated that the intervention research in the informal palliative caregiving setting has steadily progressed since 2011. There has been an evident increase in the number of RCTs, particularly for dementia (Dam et al. 2016; Elvish et al. 2013) and advanced cancer family caregivers (Chi 2016; Farelle & Wittenberg 2017). Systematic and narrative review studies have shifted focus in the last five years to reviewing specific psychosocial interventions, such as psychoeducational, or counselling-based approaches as opposed to interventions broadly. This is likely due to almost two decades of research that has encountered difficulty in synthesising findings across a wide, heterogonous literature base to draw conclusions about effect to guide policy and practice. An increased focus on technology-assisted interventions (web-based and telehealth), anchored in a desire for more flexible delivery options, is also an evident change in the intervention review literature in recent years (Boots et al. 2004; Chi et al. 2016; Farelle & Wittenberg 2017; Kaltenbaugh et al. 2015; Ploeg et al. 2017).

To provide the most coherent account of what is known about the range and effects of evaluated caregiver interventions, the following section will briefly review and examine the literature by intervention type.

2.4.2 The Range and Effects of Caregiver Interventions

Informal palliative caregiver interventions are variously defined and categorised in the literature (Northouse et al. 2010; Pasacreta & McCorkle 2000). For the purposes of this thesis, interventions will be described across five overarching categories: 1) information or education-based approaches, 2) psychoeducational approaches, 3) counselling and

psychotherapy-based interventions, 4) social support and 5) respite. Given the large number of high-quality systematic reviews in this area, an exhaustive review of caregiver intervention studies is not required and therefore falls outside the scope of this chapter. Instead, this section draws upon these reviews and key papers to outline the evidence for various caregiver interventions.

Information or Education-based Approaches

Information or education-based approaches are single component interventions intended to increase caregiver knowledge around specific subject areas. Such interventions aim to address unmet caregiver needs for adequate and timely information, particularly around managing care and accessing services which are well documented in the literature (Andershed 2006; Bee, Barnes & Luker 2009; Brobäck & Berterö 2003; Kalnins 2006; Funk et al. 2010; Morris et al. 2015). A recent review by Farquhar et al (2016) identified 49 educational interventions for carers of patients with advanced disease, most commonly cancer. Most educational interventions were delivered in an individual format (n=27), as opposed to a group format (n= 17) or as standalone resources (n=5). Most were offered as a series of 60-90 minute-sessions, over 2-3 weeks, delivered face-to-face, primarily in clinical settings. Just over half of the studies targeted caregivers specifically, as opposed to patient–caregiver dyads. Whilst Farquhar and colleagues (2016) noted all reviewed studies reported 'some form of positive data' (p 6), they cautioned that across studies there was 'suboptimal' reporting of intervention type, content, dosage, caregiver population, attrition, and data collection processes. Additionally, they determined a heightened risk of bias due to the developers of interventions undertaking their evaluation. Consequently, there is insufficient evidence to support these interventions.

In the dementia caregiver setting, a review and meta-analysis of seven RCTs of educational interventions for family dementia caregivers (n=764) found evidence for a moderate effect on caregiver burden and a small effect for depression (Jensen et al. 2015). Educational interventions were found in another review of end-of-life caregivers to positively affect caregiver knowledge, self-efficacy and satisfaction with care, but not general psychological health or coping skills (Chi et al. 2016). The evidence for the effectiveness of single component information or education interventions for caregivers is therefore, not conclusive.

Psychoeducational-based Interventions

Psychoeducational approaches are multi-component interventions including both educational and supportive elements. For example, whilst commonly delivered as structured programs to build knowledge and skill in areas such as stress management and care provision, they also incorporate emotional or psychological support. Given the known psychological burden associated with caregiving it is not surprising that there have been several psychoeducational strategies developed to improve caregiver outcomes.

Psychoeducational approaches have received the greatest amount of evaluation in the informal caregiving literature, particularly with RCT designs (Ferrell & Wittenberg 2017; Northouse et al. 2010) and demonstrate the most consistent effects across studies (Applebaum 2013; Chi et al. 2016; Eager et al. 2007; Hebert & Schulz 2006; Hudson, Remedios & Thomas 2010). A systematic review and meta-analysis of supportive intervention studies (n=78) for predominantly dementia caregivers, found psychoeducational interventions to have a small to moderate effect on reducing caregiver burden and depression and increasing subjective wellbeing, satisfaction with caregiving, as

well as knowledge and ability to provide care (Sörensen, Pinquart & Duberstein 2002). Other reviews have similarly found evidence for psychoeducation interventions to increase caregiver knowledge and ability to provide care in various stage of illness (Applebaum & Breitbart 2013; Chi et al. 2016). Holm and colleagues (2016) developed and evaluated a group based psychoeducational intervention for family caregivers (n=119) consisting of 3 weekly-sessions of 2 hours, in a RCT. There were no significant findings of effect for caregiver burden, health, anxiety, depression or caregiver reward. Small effect sizes were found for increased caregiver preparedness both post intervention and at 2-months follow-up, and competence in caregiving, post intervention, compared to a treatment as usual control. The authors suggested that small to moderate baseline levels of anxiety, depression and caregiver burden could account for the small effect sizes. Another RCT of informal palliative caregivers (n=298) by Hudson et al. (2015) evaluated a nurse led psychoeducational intervention involving the delivery of tailored information and resources to increase preparedness for caregiving and to promote psychological wellbeing. The intervention, consisting of one visit and three phone calls, had a significant small to medium effect on decreased distress 8-weeks post the death of the care recipient, compared to a treatment as usual control group.

Whilst the existing body of evidence appears to suggest that psychoeducational programs are more effective for improving psychological functioning than purely education or information-based interventions, effect sizes are modest (Hebert and Schulz 2006). Additionally, reviews continue to note that psychoeducational models are still orientated primarily towards patient content and increasing preparedness for caregiving, as opposed to teaching and supporting caregivers to care for themselves and their own needs (Ferrell & Wittenberg 2017).

Counselling and Psychotherapy-based Interventions

Counselling and psychotherapy-based approaches are predominantly delivered one-to-one, or to patient-caregiver dyads. They are founded on a 'therapeutic alliance' with a practitioner and focused on emotional, psychological and behavioural change to help individuals gain agency over their stressors. In a Cochrane Review of interventions for end-of-life caregivers, emotional support was identified as a common feature of effective interventions that reduced psychological distress (Candy et al. 2011, p 23). Other studies have reported no effect from counselling or psychotherapy (Kozachik et al. 2001). Cognitive Behavioural Therapy (CBT), one of the most commonly used psychotherapies within counselling interventions in the end-of-life caregiving setting, has demonstrated increasing evidence of efficacy. Cognitive behavioural interventions have been found to significantly improve family caregivers' psychological health (anxiety, burden, strain and mood), coping skills, self-efficacy and quality of life for end-of-life caregivers (Chi et al. 2016). They have also been found to reduce depression in dementia caregivers (Gallagher-Thompson & Coon 2007) and psychological distress in mixed stage cancer caregivers (Applebaum & Breitbart 2013). A meta-analysis by Sörensen, Pinquart and Duberstein (2002), reported that psychoeducational support interventions using a cognitive behavioural approach have been found to offer the most consistent beneficial effects for decreasing caregiver burden, depression and improving general wellbeing. This points to the potential value of multi-component interventions. The resource intensive nature of delivering psychological and counselling-based interventions, primarily in a one-to-one setting over several sessions, has been noted as a limitation in the literature (Aoun et al. 2012b). Further, caregiver uptake of

counselling or psychotherapy-based approaches have been found to be low (Mosher et al. 2013a; Ussher et al. 2009; Vanderwerker et al. 2005). Therefore, whilst potentially effective at reducing psychological symptoms, psychotherapeutic interventions incorporating a CBT component, may not be widely available or taken-up by many informal palliative caregivers.

Social Support

Social support interventions often take the form of peer support groups, providing the opportunity to interact with and gain support from others in a similar situation and address social isolation, common to end-of-life caregiving (Bloom 2000). Caregivers have been shown to have variable preferences in terms of social engagement and to encounter challenges in regular attendance due to caregiving logistics and responsibilities. The efficacy of social support groups as documented in the literature is mixed (Dam et al. 2016). A systematic review of dementia caregiver group-based interventions between 1998-2009 found that whilst psychoeducational groups significantly reduced depression, caregiver burden and increased psychological wellbeing, no significant effects were found regarding social support group interventions (Chien et al. 2011).

Qualitative studies have demonstrated more positive outcomes of social support approaches than quantitative studies, suggesting perhaps that outcome measures may not be well matched to the goals addressed by the intervention. Qualitative findings have identified the benefits of social support interventions as decreased isolation, increased emotional support, social inclusion, development of new social contacts (Dam et al. 2016), acquisition of useful information and a sense of belonging (Henriksson & Andershed 2007; Milberg et al. 2005; Witowski & Carlsson 2004). Henriksson et al. (2013) delivered and evaluated 11 support group interventions for caregivers of patients with life threatening

illness during ongoing palliative care in 2009. Interventions included 6 weekly-sessions beginning with 30- minutes social conversation followed by a guest speaker who presented different topics. No significant effects were found for measures of hope, anxiety or depression. However, moderate effect sizes were found for increased preparedness for caregiving and small, but significant effects for caregiver competence compared to the control group. Like information-based interventions, evidence for social support groups to provide positive effects for informal palliative caregivers is mixed. Further qualitative studies may help to identify outcome measures that more closely match the effects reported by caregiver participants.

Respite interventions

The provision of respite, commonly defined as a temporary 'interval of rest and relief' (Strang 2000, p 14) from caregiving responsibilities, has been the mainstay of efforts to support the mental and physical health of caregivers caring at the end of life (McGrath et al. 2006; Wolkowski, Carr and Clarke 2010). Categorised in the review literature as a practical resource or intervention (Kristjanson 2003), the provision of respite in its various forms (inpatient, day or in-home respite) attempts to address one of the most frequently cited unmet caregiver needs: a break or 'time out' from caregiving. Despite respite being a long-established form of caregiver support, there has been surprisingly limited intervention research into its effectiveness, with many authors determining that perceived benefits of respite are based more on the assumption of benefit, than on empirical evidence (Arksey et al. 2004, Henwood, Larkin and Milne 2017; Ingleton et al. 2003; Strang 2000; Strang et al. 1999; Thomas et al. 2017; Wolkowski, Carr and Clarke 2010). Underpinning reasons for limited evaluation include the lack of consensus on the definition of respite and what it

entails, (O'Shea et al. 2017a; Payne et al. 2004b, Satterley 2007; Wolkowski, Carr & Clarke 2010), diverse views on whom should be the intended beneficiary of respite, that is, the caregiver or care recipient (Ingleton et al. 2003) and intended outcomes (Henwood , Larkin & Milne 2017; Payne et al. 2004b; Thomas et al. 2017).

Existing research has produced mixed findings of the effectiveness of respite in end-of-life caregiving, particularly regarding the delayed institutionalisation and reduced negative effect on caregiver physical and mental health (O'Shea et al. 2017a; Strang et al. 1999). Two recent reviews in the family dementia caregiving space Maayan, Soares-Weiser and Lee (2014) and Vandepitte et al. (2016) have attributed these mixed findings to the diversity of respite interventions and a lack of exploration of the 'quality' of these respite experiences. For example, historically, respite has been regarded to be 'a service', provided with the view that temporary removal of the caregiver or care recipient to enable a physical break would result in an experience of reprieve or respite from caregiving (O'Shea 2017b; Strang 2000). Qualitative research exploring caregivers' experience of respite has revealed that a cognitive and emotional break, in addition to a physical break from caregiving are integral features to a beneficial and 'quality' respite experience (Laverty, Arber & Faithfull 2016; Strang, Koop & Peden 2002). There is now a growing argument in the literature for respite to be reframed as 'a psychological outcome' rather than 'a service' (Chapple, Reid & Dow 2001; O'Shea et al. 2017a; Strang 2000). Whilst this would provide for the possibility of envisaging a broader range of support options to facilitate a respite experience, to date respite models have retained their traditional form.

Despite caregivers frequently expressing the need for a break or time away from caregiving, low uptake of respite care is consistently reported across studies (Harding &

Higginson 2003; Ingleton et al. 2003; Wolkwoski, Carr & Clarke 2010). Various factors underlying caregiver reluctance to engage respite care have been identified. These factors include guilt (Myren et al. 2013; Upton & Reed 2005); a perception of abandoning the care recipient (de la Cuesta-Benjumea 2011; Phillipson & Jones 2011; Upton & Reed 2005), especially when time is limited (Payne et al. 2004b); not wanting to relinquish control (Phillipson, Jones & Magee 2014); and conceptualisation of respite as a 'luxury' or a non-legitimate need (Ugalde, Krishnasamy & Schofield 2012). Additionally, access to respite services has been reported as disparate across Australia and frequently only presented as an option in the case of crisis or an emergency (Palliative Care Australia 2008). It may also be that respite hasn't been provided in an acceptable format in a way that caregivers can operationalise their needs for a break or a temporal space in which to rest or replenish (Wolkowski, Carr & Clarke 2010). Harding and Higginson (2003, p72) state, 'the respite literature has rarely answered questions of acceptability among this population'.

2.4.3 Making Sense of the Intervention Evidence

Having presented the different types of informal palliative caregiving support interventions and their findings of effect, this section distils how we can make sense of this body of literature and what it means.

Up until the last 5-10 years, development and examination of caregiver support interventions has been limited, particularly in comparison to the body of research of caregiver needs and outcomes, (Harding et al. 2012b; McMillan 2005; Pope et al. 2017). Henwood, Larkin & Milne (2017, p 92) offer a very sharp critique of the existing caregiver intervention literature, making the following assessment:

> Much of the carer-related knowledge is focused on: describing and quantifying the carer population profile in terms of numbers and characteristics; documenting the impact and sequela of caregiving in a 'burden of care' narrative and to a lesser extent, evaluating support for carers, usually within narrow cost effectiveness parameters of 'what works' in enabling carers to continue caring.

Drawing definitive conclusions about the efficacy of caregiver support interventions from the available evidence is difficult. This is due to a dispersed and ill-defined literature base and the heterogeneity of study design, intervention content and type, mode of delivery, as well caregiver populations of interest and the outcomes measured (Candy et al. 2011; Eager et al. 2007; Hudson, Remedios & Thomas 2010; Northouse et al. 2010). These factors preclude consensus about what interventions are most effective, for whom, in what format, how much or why (Grande et al. 2009; Schildmann & Higginson 2010).

Across the different types of informal palliative caregiver interventions reviewed in this chapter, psychoeducational and skill-based approaches are the most evaluated caregiver support intervention and demonstrate the most consistent effects for increased preparedness and competence. Psychotherapeutic approaches, particularly those using CBT have been found to have the strongest effect on psychological distress and depression (Gallagher-Thompson & Coon 2007). Studies of social support groups have produced findings of mixed effect, and respite care, whilst the most commonly offered caregiver support intervention, lacks rigorous empirical investigation. The finding, across studies, of consistently low uptake of respite services, despite high unmet needs for 'a break from caregiving', flags an area for greater research attention to determine more acceptable respite models.

There is stronger evidence of positive effects for multicomponent approaches (Cruz, Marques & Figueiredo 2017; Dam et al. 2016; Gallagher-Thompson & Coon 2007; Grande et al. 2009; Hebert & Schulz 2006; Hudson 2005; Lorenz et al. 2008; Schulz & Martire 2004; Sörensen, Pinquart & Duberstein 2002). There is also evidence for targeted interventions, tailored to individual caregiver needs, to produce more robust treatment effects (Applebaum et al. 2014; Hebert & Shulz 2006; Hudson, Remedios & Thomas 2010; McCorkle & Pasacreta 2001; Ussher et al. 2009). However, such interventions are lacking within the caregiving literature (Hudson et al. 2012). Overall studies have found greater effects for increasing caregiver knowledge and skills, than for decreasing depression and caregiver burden (Hebert & Shulz 2006) and for caregivers with high baseline distress (Andrykowski & Manne, 2006; Kissane et al. 2006; Ussher et al. 2009). Whilst some authors have argued for targeting carers with higher levels of distress (Carlson et al. 2000), others have argued for the need for proactive interventions to prevent high levels of distress in the first place (Grande et al. 2009). The most effective time point of offering supportive interventions in terms of the caregiving journey and the patient illness trajectory, also remains unclear (Candy et al. 2011). The literature also offers little in evidence around the required 'dose' (Eagar et al. 2007) or amount of intervention required for positive effect, nor the active components producing beneficial change in caregiver interventions (Ussher et al. 2009).

The Challenge of Engaging Caregivers in Support Interventions

Despite the availability of support approaches, there are well documented challenges to securing caregiver engagement with such interventions and support. These challenges are underscored by both caregiver and system factors. For example, caregiver reluctance to disclose and seek support for themselves, even when experiencing a range of

unmet needs, is consistently reported across studies (Funk et al. 2010, Ugalde, Krishnasamy & Schofield 2012; Aoun et al. 2015a). Harding and Higginson (2001), in a qualitative study of 18 family caregivers in the UK described this phenomenon as 'caregiver ambivalence', underpinned by several factors. These included: (1) the lack of identity or being perceived by others as an extension of the patient, (2) a choice to defer their own needs and self-interests until bereavement, (3) not regarding themselves as legitimate service recipients, (4) an unwillingness to leave the care recipient, and (5) the adoption of distraction and avoidance strategies, as opposed to engaging with their own experience and needs (Harding and Higginson 2001). Other reasons elucidated in the literature include, not wanting to divert focus from the care recipient (Payne, Smith & Dean 1999; Ventura et al. 2014), a perception of self-care as selfish (Ugalde, Krishnasamy & Schofield 2012) and personal values such as self-reliance and stoicism (Candy et al. 2011; Radbruch & Payne 2010; Soothill et al. 2003).

System factors also underpin challenges to caregiver engagement in supportive interventions. One such factor is the gearing of resources and focus towards meeting the complex and rapidly changing patient needs, which makes the operationalisation of the palliative care ethos of family support difficult to achieve in practice (Hudson, Remedios & Thomas 2010). As Zapart et al. (2007, p 98) states:

> The provision of community based palliative care in spite of the intent to incorporate the needs of the carer, often overlooks or regards these as secondary to those of the patient.

Additionally, a lack of structured approaches to caregiver need assessment is widely reported in the literature, despite caregiver assessment being strongly advocated (Aoun et

al. 2015a; Ewing & Grande 2013; Osse et al. 2006). Other studies have found that even when caregivers identify their needs, the uptake of strategies, resources and interventions to support these needs can be low (Sun et al. 2015; Zapart et al. 2007).

Whilst caregivers report a range of unmet needs and despite the availability of different support interventions, engaging caregivers in supportive interventions is a challenge, underpinned by both caregiver reluctance to consider support for themselves and their own needs, and as a result of system-based factors. This is a clearly an important area for further research.

Methodological Limitations

It is important to recognise that the reviewed caregiver intervention studies share methodological limitations; some unique to this area of research and others are present across the broader palliative care literature. Specifically, there is a limited window to engage caregiver participation in research before caregiving demands intensify and death of the care recipient occurs (Grande et al. 2009, Harding et al. 2011). Additionally, participant samples are commonly small, non-representative samples, comprised mostly of female, white, higher educated, heterosexual caregivers living in metropolitan areas (Eagar et al. 2007; Evans et al. 2013; Schildmann & Higginson 2011; Steinhauser et al. 2006). The predominant method of recruiting caregiver research participants is through known and trusted sources such as palliative or hospice services. Whilst proven as one of the most effective recruitment methods in end of life research (Whitebird et al. 2011), this practice has likely resulted in more distressed caregivers not being offered the opportunity to participate in research. Further, existing knowledge is skewed in the direction of caregivers receiving services and may not be indicative of those caring in the absence of formal

support. An additional criticism of dyad caregiver intervention studies is a failure to differentiate the data that pertains to caregivers from the care-recipient, and to specify for whom the intervention is primarily designed (Ussher et al. 2009).

Limitations of quantitative studies have included the use of small sample sizes, which are often underpowered to detect effect, the lack of active control groups (Candy et al. 2011; Harding et al. 2012b) and the multiplicity of caregiver outcome measures used across studies, many of which have not been validated for use in a palliative caregiving context (Michels et al. 2016). Among qualitative studies, which are discernibly fewer in number than quantitative studies in the field of caregiver intervention research, reliance on retrospective study designs is a common criticism (Steinhauser et al. 2006). It is argued that retrospective study designs have missed important experiences, effects and perceptions as they are occurring (Stajduhar et al. 2010). A lack of longitudinal studies in both qualitative and quantitative research is also a noted and therefore, there is a deficit in understanding how effects and experience change over time. Further, across both quantitative and qualitative fields, there is under-reporting of recruitment processes, reasons for study refusal, participant attrition, as well as vague description of intervention content and process. This has made the determination or research bias and study quality a more complex task.

Many of these identified methodological limitations likely reflect that caregiver intervention research is a relatively new field of inquiry, with the research gaze having been more firmly focused on exploring patient experience and interventions.

2.4.4 What is Missing in the Literature and why is it Important?

In reviewing the informal palliative caregiver intervention research, it is very evident, that despite the increased focus on caregiver interventions in the last 5-10 years, several

significant silences in the literature remain. Among these, and pertinent to this study, are firstly a lack of interventions with a specific focus on caregiver self-care, and secondly, a limited qualitative understanding of caregivers' preferences and experiences of interventions. These significant gaps in knowledge and their implications for practice and research are explored in the following section.

A Lack of Holistic, Self-Care Interventions for Caregivers

Whilst it is well understood that caregivers experience a range of complex unmet needs spanning emotional, psychological, physical, social, spiritual, financial and practical domains, it is striking from reviewing the literature, how this is not matched with an equally diverse range of intervention types to support caregivers' holistic needs. For example, there are limited number of existential or spiritual interventions for informal palliative caregivers (Applebaum et al. 2014; Duggleby et al. 2007), despite widely documented unmet needs for spiritual and existential support, (Applebaum & Breitbart 2013; Duggleby et al. 2014; Kristjanson, Aoun & Yates 2006; Murray et al. 2004; Stajduhar et al. 2010; Ventura et al. 2014). The reviewed interventions were overwhelmingly focused on increasing knowledge, skill and preparedness to care for the care recipient, many of which had a latent or explicit purpose of enhancing the quality and sustainability of patient care. This has led to a dearth of developed and trialled interventions that specifically focus on supporting and resourcing caregivers to take care of themselves across the holistic domains of wellbeing. For example, Ferelle (2017a) noted in a review of 50 RCTs of interventions for family caregivers of cancer patients, that 72% of psychoeducational intervention content focused on patient care. This may also account for findings in studies such as Ugalde (2011) and Merluzzi et al. (2011), of significant less caregiver self-efficacy in relation to caring for themselves, as opposed to

caring for the care recipient. Authors such as Dionne-Odom (2017a, p 2441) have strongly asserted that 'interventions should be developed to help caregivers balance the support and care they give to others, with support and care they give to themselves'.

In the absence of a single, agreed upon definition, self-care is variously described (Godfrey et al. 2011; Johnson et al. 2012; Pope et al. 2017). A 2011 review by Godfrey and colleagues (2011) identified 139 different self-care definitions across 75 studies reviewed. These extensive variations in how self-care is conceptualised in the literature has obvious implications for comparing findings across studies and for advancing the field of self-care intervention research in the setting of end-of-life caregiving. Levin (1976), considered by many as the founding father of self-care, originally conceptualised self-care as actions undertaken by patient populations to individually protect themselves against disease and promote health (Leven, Katz & Holst 1976). Self-care is now broadly understood as purposeful action, undertaken by any individual in any context throughout the lifespan, that promotes and seeks to maintain health and wellness, and which assists in coping with day to day stressors (Godfrey et al. 2011; Pope et al. 2017). Lee and Miller (2013), emphasise the holistic domains of health and wellbeing attended to in personal self-care as physical, psychological and emotional, social, leisure and spiritual.

Self-care intervention studies in the context of end-of-life caregiving did not emerge as a large body of research when reviewing the literature. Of the few descriptive studies that have explored self-care interventions in this setting, higher levels of caregiver self-care have been found to provide a range of positive effects. These include improved wellbeing (Acton 2002), enhanced quality of life (Johnston 2009), reduced caregiver stress (Lu & Wykle 2007, Merluzzi et al. 2011), and reduced caregiver burden (Merluzzi et al. 2011). Pope et al.

(2017) in a self-administered survey of 106 informal caregivers, 84% of whom were female, found that 'personal self-care was inversely associated with perceived stress and pain and directly associated with emotional wellbeing and general health' (p 831). A cross sectional US study of 294 family caregivers who were caring for a significant other with advanced cancer, found that high depression, anxiety and low health-related quality of life were associated with low engagement in self-care practice (Dionne-Odom et al. 2017a). Further, self-care is regarded by the World Health Organisation as critical to person centred health care (World Health Organisation 2019b).

Self-care interventions are regarded to invite a significant shift in perspective from the traditional health professionals as 'expert' approach in which care is delivered to passive recipients. A more empowering approach is advocated (Pope et al. 2017; Richard & Shea 2011; Wilkinson & Whitehead 2009) whereby individuals are 'given the means to master or deal with problems rather than relinquish them to others' (Johnston 2012, p 1620).

There has been an emerging interest in mind-body self-care interventions over recent years in the palliative caregiving setting, spurred by a desire to develop and offer a more holistic approach to the cultivation of health and wellbeing. This contrasts strongly to the more dominant bio-medical, disease and burden focused paradigm of care Dharmawardene et al. 2016). Such interventions have included Tai chi, yoga, music therapy, and contemplative or meditation-based interventions, which point to an increasing regard to broaden caregiver support approaches. However, findings continue to demonstrate that caregivers find it difficult to care for themselves whilst caring for a significant other, which perhaps underlies a lack of interventions in this area. These very factors indicate a need for studies to develop and trial self-care interventions to encourage and empower caregivers to

consider their own health, wellbeing and personal self-care needs as legitimate, and to support them to develop ways to attend to these.

A Limited Understanding of Caregiver Experience and Preference for Interventions

The second significant gap in the existing informal palliative caregiving intervention literature is the lack of understanding of caregiver preferences and experiences of supportive interventions. This is due to quantitative research measuring for specific outcomes, most often reduction in negative symptomology such as reduced stress, anxiety, depression and caregiver burden. As outlined, quantitative inquiry has predominated as the research approach used in caregiver intervention studies. The limited number of qualitative intervention studies is surprising considering that the broader informal palliative caregiver research of needs and experiences have been well researched by a qualitative approach.

Qualitative research into informal palliative caregiver interventions is important as it can provide a more nuanced understanding of how caregivers experience the interventions designed to support them, the challenges encountered and their perception of what constitutes meaningful effects (Craig et al. 2008; Grande et al. 2009; Hudson, Remedios & Thomas 2010; Lou et al. 2017). Without this qualitative understanding important intervention elements and effects may be overlooked. Several studies have demonstrated that quantitative measures may not be well matched to intervention effects (Harding et al. 2002; Holm et al. 2017; Ussher et al. 2009). For example, a study of a short-term intervention promoting caregiver self-care, whilst not identifying any statistically significant effects, was found by qualitative research to offer a range of benefits regarded by caregivers as significant to them. These included: validation of feelings, the opportunity to ask

questions and increase knowledge, identification with other carers and the provision of support (Harding et al. 2002).

A lack of qualitative research into caregiver interventions, also misses the opportunity to value and engage caregivers' contribution towards informing intervention design, development and evaluation, leading to an approach of 'research on' as opposed to 'research with' caregivers (Craig et al. 2008). Grande et al. (2009, p 342) strongly advocated for 'user involvement to ensure that we are indeed addressing what is important to carers in a manner acceptable to them'. Despite 10 years of literature advocating for increased informal palliative caregiver or 'consumer' involvement in development and trialling of caregiver interventions, research examples of doing so are rare. Further, the potential for researcher bias is noted as an issue within the literature, with many researchers having both developed the intervention and undertaken its evaluation (Farqhuar et al. 2016).

Of the existing qualitative intervention research, most studies remained descriptive, as opposed to offering more conceptual or theoretical explanations of caregiver experience of supportive interventions (Duggleby et al. 2017). Conceptual or theoretical frameworks would help inform intervention design, identification of key elements or active interventional components underlying benefit and the selection of more targeted outcome measures (Candy et al. 2011; Grande et al. 2009; Holm et al. 2016; Ussher et al. 2009). A mature articulation of complex factors inherent in the delivery and evaluation of carer intervention research is strongly advocated in the MORECare guidelines for end-of-life care interventions (Higginson et al. 2013).

The lack of in-depth, nuanced understanding of caregiver experience of interventions and a dearth of self-care interventions, focused specifically on resourcing

caregivers to take care of their needs, health and wellbeing, have strongly focused and informed the present study.

2.5 Chapter Summary

This chapter has defined, introduced and explained the role of informal caregivers caring for a significant other at the end of life. It has illustrated their vital contributions to the provision and sustainability of quality home care. The significant impacts of caregiving, both negative and positive, were distilled, followed by a review of the support interventions developed and trialled to mitigate the negative sequala of caregiving and to enhance the opportunity of experiencing more positive and rewarding aspects of providing care to a significant other. Specifically, this chapter has demonstrated that the content and targeted outcomes across the different types of interventions (information-based approaches, psychoeducational, counselling and psychotherapy and social support groups) have predominantly focused on increasing preparedness to manage patient care needs (Ferrell et al. 2017) as opposed to increasing caregivers' ability to care for themselves and their own wellbeing (Cruz, Marques & Figueiredo 2017; Dionne-Odom et al. 2017a). As a result, there is a relative absence of holistic self-care interventions with the central aim of resourcing caregivers to attend to their own health, wellbeing and self-care needs. Another significant and enduring gap in the caregiver intervention literature is the limited qualitative understanding of how caregivers engage with and experience support interventions and their effects.

The next chapter will explore the potential for mindfulness-based interventions to offer a new paradigm of informal palliative caregiver support, as a holistic self-care intervention, through a critical review of the mindfulness-based intervention literature.

CHAPTER 3

MINDFULNESS-BASED INTERVENTIONS FOR CAREGIVERS: A REVIEW OF THE LITERATURE

3.1 Chapter Introduction

The previous chapter highlighted a need to develop and trial interventions that have an explicit focus on supporting the multidimensions of caregiver health, wellbeing and self-care. Mindfulness-based interventions (MBIs) can be described as an empowering holistic approach to stress management. MBIs have offered a range of benefits across the biopsychosocial domains of health in other populations by teaching participants to develop insight into, and regulate their responses to, challenging experiences. In the void of self-care interventions for informal palliative caregivers, it is of interest to explore the potential of mindfulness as a new supportive approach or form of self-care in this setting.

This chapter explores the published literature to determine what is known about the potential benefits of MBIs for informal palliative caregivers and what there is still to know. The chapter is organised in two main sections. The first provides an overview of the mindfulness-based intervention literature broadly; the second offers a critical review of the application and evidence base for MBIs to support informal palliative caregivers. Explicit connection will be drawn between silences in the literature and the questions asked within this thesis, as well as the methodological choices made in the pursuit of answering them.

3.2 An Overview of Mindfulness-based Interventions and their Effect

This section explains the construct of mindfulness, as conceptualised within Buddhist traditions and its subsequent translation into a secular intervention in psychological and physical health settings. The range of MBIs and their central tenants are presented, along with a brief overview of both quantitative and qualitative findings of effect across different populations.

3.2.1 Introducing Mindfulness

Mindfulness has attracted burgeoning clinical and research interest over recent decades as a psycho-social intervention. Beginning primarily within health-care settings, this interest and application has now reached into diverse sectors including education, business, law, sport, government and leadership (Williams & Kabat-Zinn 2011). The American Mindfulness Research Association (AMRA) examined the research literature for mindfulness publications by year from 1980–2018, finding a 575% increase in the number of academic journal publications between 2010-2018 alone. Mindfulness, however, is far from a contemporary concept. It is a core philosophy and practice deeply embedded in Buddhism, an ancient spiritual tradition that extends over 2500 years (Gethin 2011). Whilst mindfulness, as a construct, can be found in a range of other spiritual traditions, authors argue that it is more systematically integrated and articulated in Buddhism (Keng, Smoski & Robins 2011, p 1042). While it is beyond the scope of this thesis to present a detailed exploration of mindfulness as expressed in the different Buddhist schools and traditions, it remains important to acknowledge the origins of mindfulness-based interventions within western psychological and physical health contexts.

3.2.2 The Buddhist Origins of Mindfulness

In a Buddhist context, the Pali word of 'sati' represents one of the earliest references to the construct of mindfulness. The English translation of 'Sati' as mindfulness, was first offered by TW Rhys Davids in 1881, and transcribed as an act of 'remembering' or repeatedly 'calling to mind' the impermanent nature of all phenomenon and human experience (Gethin 2001; Bodhi 2011; Chiesa 2013). Emphasis was placed on attending to changing experience, in any given moment, without evaluation. In Buddhism, mindfulness is regarded as a means to insight and the cessation of mental suffering or 'dukkha', which is perceived to be founded in the relentless craving and judgemental activities of the mind (Cheisa 2013). In this view, the cause of human suffering lies more in how people perceive what is happening in their lives and their wish for things to be different, as opposed to the events in and of themselves. Beyond a series of practices, mindfulness was also perceived as a way of being, or an approach to everyday life that was imbued with an ethical aspect (Cheisa 2013; Purser & Milillo 2015).

3.2.3 Mindfulness within Secular Psychological and Physical Health Settings

The conceptualisation and application of mindfulness in western psychological and physical health contexts began with the pioneering work of American Jon Kabat-Zinn in 1979, when he created the first mindfulness-based stress reduction program (MBSR). MBSR was initially developed as a behavioural medicine approach to help reduce pain and suffering among chronic pain patients (Kabat-Zinn 2003). Whilst inspired by a range of Buddhist and Yogic traditions, Kabat-Zinn created a secularised mindfulness program with the view that this would best support engagement by western populations in the health arena.

Kabat-Zinn's definition of mindfulness is the most commonly cited in the psychological literature and the one adopted in this thesis. Mindfulness is defined by Kabat-Zinn as awareness that comes from 'paying attention in a particular way: on purpose, in the present moment and non-judgmentally' (1994, p 4). This definition emphasises an intentional regulation of attention on the thoughts, feelings and sensations that emerge in the context of present moment experience from a non-elaborative or non-judgemental position. Regular formal mindfulness practice is perceived as the 'scaffolding' used to deepen understanding and hone the skill of mindfulness (Kabat-Zinn 2005; Shapiro et al. 2006). Varied conceptualisations of mindfulness have since evolved, which has made obtaining a universally agreed definition of mindfulness a complex task (Fletcher & Hayes 2005; van Dam et al. 2018b). Influenced by their different disciplines and experiences of mindfulness, researchers, clinicians and practitioners emphasise different elements of the construct of mindfulness (Brown & Ryan 2007). For example, mindfulness has been described in the literature as a trait (Giluk 2009; Mesmer-Magnus et al. 2017) or state like quality (Egan, Hill & Foti 2017) and 'as a psychological process, an outcome, a specific technique, or as a general method or collection of techniques' (Fletcher and Hayes 2005, p 317). Mindfulness has also been described as a single construct of 'attentional regulation' (Brown & Ryan 2003; van Dam et al. 2018a) or consisting of a range of components including 'attention and acceptance' (Bishop et al. 2004) or 'attention, acceptance and intention' (Shapiro et al. 2006). Other authors, such as Grossman (2015), emphasise the original ethical aspect of mindfulness, which is regarded to have been diluted in the application of mindfulness in psychological and health-care settings.

It is important to note that the secularisation of mindfulness for application in western psychological and physical health settings and its attendant definitions has

attracted much debate over the last 30 years and continues today. There is a view that contemporary MBIs represent a gross 'denaturing', 'simplification' and 'de-contextualisation' of mindfulness practice, as contained within an ancient, rich Buddhist context (Purser & Milillo 2015). The contrasting view is that Kabat-Zinn's approach of introducing mindfulness into mainstream secular settings constituted a skilful re-contextualisation of mindfulness (Sun 2014). This argues that mindfulness was incorporated into a western model 'in the service of helping to reduce suffering' (Williams & Kabat-Zinn 2011, p 3), enabling access for a greater number of people who may not otherwise have engaged with mindfulness in its more ancient, eastern form (Sun 2014). Whilst diverse definitions of mindfulness persist, the general consensus is that mindfulness is composed of at least two factors: the self-regulation of attention on present moment experience and a non-judgemental accepting orientation (Chiesa, Anselmi & Serretti 2014, p 124). The research literature reflects these different positions and tensions.

3.3 Mindfulness-based Interventions

Mindfulness-based Interventions (MBIs) is an umbrella term used to refer to a range of mindfulness programs developed and applied in the context of psychological and physical health care. The following section will briefly outline the range of mindfulness-based interventions, including the two most established and well known: mindfulness-based stress reduction (MBSR) and mindfulness-based cognitive therapy (MBCT), as well as others subsequently established.

3.3.1 The Mindfulness-based Stress Reduction Program (MBSR)

The mindfulness-based stress reduction program (MBSR) developed by Jon Kabat-Zinn (1979) represented the first western application of mindfulness into a group-based psychological support intervention. MBSR is a structured psychoeducational group program, as opposed to a group-therapy program. However, it is anchored in the experiences and challenges expressed by group participants, as opposed to a prescriptive, facilitator driven approach. The program traditionally consists of 8 weekly-sessions of 2.5-hours duration. There is an additional silent retreat day between weeks six and seven, to enable a more immersive mindfulness experience. In undertaking MBSR, participants learn, through a range of mindfulness meditation exercises, to cultivate and sustain attention on their present moment experiences without judgement. They are encouraged to take the position of 'observer' of their thoughts, feelings, and physical sensations as they occur in the moment without seeking to change them, avoid them, or become swept away in past or future concerns. Piet, Würtzen & Zachariae (2012, p 1008) described this as gaining 'the ability to step back from analytic thought and verbal problem solving to simply allow experience to be as it is'. Regular mindfulness practice supports participants to gain increased awareness of their thoughts, feelings and what is happening around them and a capacity to respond, rather than react in habitual and often unhelpful ways to internal and external stressors (Shoham et al. 2017; Segal, Williams & Teasdale 2018).

The range of meditation exercises practised within group MBSR sessions include lying and sitting practices, gentle hatha yoga movement practices and walking meditations. Participants are encouraged to practise these mindfulness exercises at home, with 45-minutes of daily practice recommended. These sessions are often referred to as 'formal

mindfulness practice'. Informal mindfulness practice is also encouraged, that is, undertaking normal daily activities in a mindful way, such as mindfully eating and mindfully listening to generalise the capacity to be mindful in all of life. Within group sessions, 'enquiry' is another important feature of MBSR, allowing discussion between participants and the mindfulness facilitator about emerging practice issues. MBSR programs, beyond their initial inception for chronic pain patients, have frequently been offered as heterogeneous group programs, open to individuals experiencing a diverse range of life circumstances, issues and stressors. This is underpinned by a view that, whilst challenges vary, facing difficulty is a universal and normal human experience (Kabat-Zinn 2013).

3.3.2 Mindfulness-based Cognitive Therapy

Mindfulness-based cognitive therapy (MBCT) is an adaptation of MBSR originally designed for the treatment of relapsing depression (Segal, Williams & Teasdale 2018). Like MBSR, MBCT is a manualised 8-week program but incorporates facets of cognitive therapy in addition to mindfulness training. MBCT includes a more intentional psycho-educational approach of supporting participants to understand the interconnection between negative, habitual thoughts and depressive symptoms. Further, MBCT aims to provide participants with a way to:

> Recognise the automatic activation of dysfunctional thought processes, including depression-related rumination, and to disengage from these by redirecting attention to experience as it unfolds and changes moment by moment (Piet, Würtzen & Zachariae 2012, p 1008).

Unlike traditional CBT models, which engage participants to change the content of their thoughts, MBCT is perceived to support participants to change their relationship with their

thoughts, moving toward a more de-centred and less entangled position (Teasdale et al., 2000; Segal, Williams & Teasdale 2018). Rather than relating to their thoughts as fixed truths, participants are invited to consider and experience their thoughts as passing mental experiences that can be observed, as opposed to reacting to them. This is founded on an attempt to disrupt automatic patterns of reaction and creating the possibility of stimulating more helpful responses with mind, body and action (Segal, Williams & Teasdale 2018; Shoham et al. 2017).

3.3.3 Other Mindfulness-based Interventions

Other interventions utilising a mindfulness approach and referred to as mindfulness-informed programs (Crane and Reid 2016), due to having a mix of other components, include dialectical behaviour therapy (DBT) (Linehan 1991) and acceptance and commitment therapy (ACT) developed by Hayes (1982). DBT is an intervention combining the principles of cognitive behavioural therapy and mindfulness, with a specific focus on supporting patients who have a borderline personality disorder or extreme psychological dysregulation (Linehan 1993). Acceptance and commitment therapy (ACT) was developed as an approach to counter emotional avoidance and enhance behavioural change (Hayes & Wilson 1994). ACT is a behavioural and cognitive model that combines traditional psychological methods with acceptance, mindfulness and values. Its specific focus is to foster greater psychological flexibility in relating to difficult emotions, thoughts and experiences and to support behaviour more consistent with what individuals' value (Low et al. 2016).

Mindfulness-based interventions have also been specifically developed for different populations and their salient challenges, but are less widely implemented or researched than MBSR, MBCT, DBT and ACT. Examples include, but are not limited to, Bartley's (2011)

mindfulness -based cognitive therapy for cancer (MBCT- Ca); mindfulness-based elder care (McBee 2009); Duncan and Bardacke's (2010) mindfulness-based child birth and parenting (MBCP); Witkiewitz, Marlatt & Walker's (2005) mindfulness-based relapse prevention (MBRP) and mindfulness-based eating awareness training (MB-EAT) for binge eating and related disorders by Kristeller & Wolever (2010).

To support participants where time and life pressures make engagement difficult, adapted methods of delivering MBIs have also developed over time. These have deviated from the traditional 8-week face-to-face group programs of 2–2.5 hours, with daily home practice requirements of 45-60 minutes. For example, some approaches delivered brief or so called 'lower dose' protocols of reduced number and duration of sessions and reduced home practice requirements (Basso et al. 2019; Blanck et al. 2018). Mindfulness programs have also been offered as individual training and in other than face-to-face formats, such as online, via telephone, or through supported self-study options such as mindfulness-based smart phone apps.

3.3.4 Maintaining Intervention Integrity

To ensure intervention integrity and efficacy, there is a strong consensus in the literature that mindfulness-based interventions need to be delivered by skilful, experienced and well-trained facilitators (Crane et al. 2013; Dobkin 2014; Kabat-Zinn 2003; Piet, Fjorback & Santorelli 2016; Shonin & Van Gordon 2015). Additionally, it is strongly advocated that facilitators have an established and ongoing self-practice of mindfulness themselves:

> No matter what modifications are made to the basic program, given the clearly stated importance of who teaches the program and how this is done, instructors

need to be practising what they teach, or they will miss the mark (Dobkin, Hickman & Monshat 2014, p 716).

To this end, attributes of skilled facilitators, supervision models, competency scales, recommended pre-facilitator training experiences and expectations of an established and ongoing self-practice of mindfulness, have been identified and postulated as best practice requirements for MBI facilitators (Crane et al. 2013; Crane 2017; Dobkin, Hickman & Monshat 2014; Evans et al. 2015). Tensions exist, however, around the length and intensity of training required in this best practice model. With an increasing popularity and demand for MBIs in the community and across diverse health, social, industry and government settings there is a need to rapidly expand the pool of mindfulness teachers and to balance intervention integrity with the fiscal and time limited requirements from individuals and services (Mindfulness All-Party Parliamentary Group (MAPPG), 2015). It has been argued that these issues can compromise the ethics, processes, outcomes and authenticity of MBIs (Crane 2017b).

3.4 The Evidence for Mindfulness-based Interventions Across Populations

This section briefly outlines the research evidence for mindfulness-based interventions broadly across populations. In doing so, it offers a frame of reference against which to place a comprehensive review of the application and evidence of MBIs for informal palliative caregivers, which is the central concern of this thesis.

3.4.1 Quantitative Findings of Effect

The effects of MBIs have been evaluated by a large and exponentially expanding body of research over recent decades. The evidence, which includes many systematic

reviews, suggests that MBIs provide many psychological and physical health benefits for diverse clinical and non-clinical populations (Bohlmeijer et al. 2010; de Vibe et al. 2017; Eberth & Sedlmeier 2012; Fjorback et al. 2011; Grossman et al. 2004; Hoffman et al. 2010; Keng et al. 2011; Khoury et al. 2015; Musial et al. 2011). Small to moderate effect sizes are commonly reported for positive mental health related outcomes in active controlled studies using conditions such as psycho-education, supportive therapy, relaxation and art therapy (Khoury et al. 2013). Larger effects sizes have been found for uncontrolled studies and when treating psychological, as opposed to physical disorders (Khoury et al. 2013).

The most consistent and robust effects of MBIs, demonstrated by an increasing number of randomised controlled trials, are for reduced anxiety (Anderson et al. 2007; Green & Bieling 2012; Hofmann et al. 2010); reduced psychological distress and perceived stress (Bränström et al. 2010; Chiesa & Serretti 2009; Oman et al. 2008; Shapiro et al. 2005; Speca et al. 2000, Williams et al. 2001) and reduced depression (Anderson et al. 2007; Carolson, Goodey & Angen et al. 2000; Koszycki et al. 2007; Sephton et al. 2007; Shapiro, Schwartz & Bonner 1998; Fjorback et al. 2011). Strong evidence exists for mindfulness-based cognitive therapy (MBCT) in reducing the risk of relapsing depression in patients with three or more previous episodes (Fjorback et al. 2011; Keng et al. 2013; Kuyken et al. 2016). Subsequently, governments such as those in the United Kingdom, have advocated MBCT as the treatment of choice for patient populations suffering from major depressive disorder (MAPPG 2015; Segal, Williams & Teasdale 2018) and have funded access to MBCT programs in the public health-care system in recognition of the evidence base.

MBIs have also been found to have positive effects for reducing physical symptoms such as fatigue and pain, as well as mental health comorbidities in patients with a range of

chronic health conditions, such as chronic pain (Grossman et al. 2007; Kabat-Zinn 1982; Perlman et al. 2010), Psoriasis (Kabat-Zinn, Lipworth & Burney, 1985), Rheumatoid Arthritis (Pradhan et al. 2007), Fibromyalgia (Kaplan, Goldenberg & Galvin-Nadeau 1993; Weissbecker et al. 2002), Multiple Sclerosis (Hoogerfwerf et al. 2017) and chronic heart disease (Baer 2003; Bohlmeijer et al. 2010; Norman et al 2018; Grossman et al. 2004; Sullivan et al. 2008). A growing number of studies have demonstrated improvements in physical symptoms and psychological outcomes for cancer patients, both in curative and palliative illness stages (Carlson et al. 2007; Carlson, Speca, Patel & Goodey, 2003; Johannsen et al. 2016; Shapiro et al. 2003; Tacón, Caldera & Ronaghan 2004).

Within the field of mindfulness-based interventions for caregivers, research has primarily focused on professional caregivers including nursing, medical and allied health staff, both in training and in practice. This predominant focus on professional care providers may reflect that they are regarded as a less vulnerable study population compared to informal or family caregivers. Research has established that professional caregivers, like informal caregivers, engage in complex, demanding care work, which over time can similarly have negative effects on their physical and mental health. Negative effects have been identified to include depression, anxiety, chronic stress, as well as compassion fatigue or burnout (Marine et al. 2006; Michie & Williams 2003; Walsh & Sue 2001). Such effects can also have a detrimental impact on the quality of care provided to patients (Boorman 2009).

Studies have shown MBIs to also have a range of positive effects on health provider psychological health (Shapiro et al. 2005), including meta-analytic reviews which have found moderate effect sizes for depression, anxiety, distress, stress and quality of life (Burton et al. 2017; Khoury et al. 2015). Other studies have found that MBIs can have a beneficial effect

on the quality of care provided to patients and their families in addition to improving the health and resilience of health providers themselves (Bruce & Davies 2015; Grepmair, Mitterlehner & Nickel 2008; Rushton et al. 2009).

The MBI literature has predominantly explored reduction of negative symptomology as opposed to enhanced positive effects (Cousin & Crane 2016). However, studies have shown that MBIs affect a range of positive psychological outcomes such as increased self-compassion (Shapiro et al. 2005), empathy (Shapiro, Schwartz & Bonner 1998), sense of spirituality (Astin 1997; Shapiro et al. 1998), increased mindfulness (Anderson et al. 2007; Nyklíček & Kuijpers 2008; Shapiro et al. 2008) and increased satisfaction as well as increased quality of life (Godfrin & van Heeringen 2010; Grossman et al. 2010; Koszycki et al. 2007; Kuyken et al. 2008; Nyklíček & Kuijpers 2008; Shapiro et al. 2005). It is argued that the positive effects of MBIs warrant further exploration due to their relationship with meaning in life (King 2006) and their protective properties against mental illness (De Vibe et al. 2017).

3.4.2 Evidence of Lower-dose and Modified Mindfulness-based Interventions

There are mixed reports examining the association between the amount of class contact time, home mindfulness practice and outcomes for those who learn mindfulness. Whilst some studies (Astin 1997; Davidson et al. 2003; Huppert & Johnson 2010; Speca et al. 2000) have found a positive correlation between the amount of meditation practice and benefits of mindfulness-based interventions, others have not (Carmody & Baer 2009). For example, in a review of 30 published MBSR trials, Carmody and Baer (2009) found no evidence that briefer MBSR programs were less effective than standard MBSR formats in reducing psychological distress. The authors argued that briefer or 'lower dose' mindfulness-based approaches warrant further study, particularly for populations for 'which

a longer time commitment may be a barrier to their ability or willingness to participate' (Carmody & Baer 2009, p 627). Ten years later, the need for greater inquiry into more flexible, lower dose MBIs remains (Basso et al. 2019; Blanck et al. 2018).

Research on the efficacy of MBIs delivered through online platforms and smart phone applications has also emerged in recent years. Web-based mindfulness programs have been found to be feasible (Glück & Maercker 2011) and provide stress reduction benefits for non-clinical populations (Krusche et al. 2012), reduce perceived stress and symptoms of anxiety and depression in student populations (Cavanagh et al. 2013), as well as having positive effects on mental health outcomes of clinical populations with anxiety and depression (Boettcher et al. 2014). In a recent systematic review of internet-delivered MBIs for people with chronic conditions (n=10 studies), Russell et al. (2018, p 1) found such programs to be 'more effective than usual care or wait-list groups, and self-guided interventions were as effective, as facilitator-guided interventions'. However, findings rest on a largely female sample. Research in the field of internet delivered MBIs whilst promising, is still young and requires further rigorous inquiry.

Mindfulness-based smart phone apps have also proliferated in recent years, with over 200 mindfulness apps identified in 2013, in the Google Android smartphone market alone (Plaza et al. 2013). In a later review, Mani et al. (2015), found over 500 mindfulness related apps. Further, there has been limited research to date, into the efficacy of mindfulness-based apps (Mani et al. 2015; et al. Plaza 2013; Van Emmerik, Berings & Lancee 2018). A randomised controlled trial of 81 participants with major depressive disorders found both an eight-week MBI and a behavioural activation control group, both delivered by smart phone application, resulted in large reductions in depression that endured for six

months (Ly et al. 2014). Another RCT by Howells, Ivtzan & Eiroa-Orosa (2016) found a mobile phone app 'head space' consisting of 10-minute guided mindfulness practice over 10 days, resulted in significant improvements in positive affect and depression compared to an active 'catch note' (note taking) phone app control group. More recently, Van Emmerik, Berings & Lancee (2018) undertook a RCT of 191 non-clinical participants using a MBI smart phone app compared to a wait-list control group (n=186). The authors concluded that mindfulness delivered via a smart phone app could significantly increase mindfulness and produce positive effects on general psychiatric symptoms and quality of life, the effects of which were maintained at three months follow-up. Participants in this study however, were also predominantly female and highly educated, limiting generalisability. In addition, there was a high participant dropout rate (58.6% across both conditions), with a completion rate of only 41.9% for the MIB treatment condition. Whilst mindfulness apps continue to proliferate in the smart phone market, like web-based platforms, there is a need for a greater number of robust studies to explore the efficacy of MBIs in this setting.

3.4.3 Findings Related to Challenges and Adverse Effects of MBIs

Whilst positive effects of MBIs are increasingly evidenced by research, caution is required to not regard or promote MBIs as a panacea for all psychological and physical ailments for all people, in all situations (Davidson & Dahl et al. 2018; van Dam et al. 2018b). Research in the last one-to-two years has begun to consider the potential for adverse effects of mindfulness, making the point that the original intent of MBIs were not to treat disease:

> The application of meditation and other contemplative practices as treatments for disease is a unique 21st Century phenomenon…These practices were designed primarily to actualise human flourishing (Davidson & Dahl 2018, p 64).

For a balanced view of the MBI research, this present study specifically examined the literature for evidence of risks and contraindications of mindfulness-based interventions, yielding the below findings.

Overall, in the broad range of studies reviewed, findings of adverse or harmful effects from participating in mindfulness-based interventions were rarely reported. It should also be noted, however, there has been limited research that has specifically enquired into the experience of negative outcomes for participants (Farias & Wikholm 2016; Goyal et al. 2014; Jonsson et al. 2014). Where studies have identified adverse consequences, these have largely been related to intensive emersion in transcendental type meditation practice over protracted periods of time such as silent retreats that extend for many days, weeks or months (Melbourne Academic Mindfulness Interest Group 2006). Transcendental meditation is a type of meditation practice that has a single pointed awareness, cultivated through focused attention on a single mantra or continually repeated word, which differs significantly from mindfulness meditation, which holds a more open and receptive awareness of any thoughts, feelings and sensations present in the moment. Negative outcomes cited in these transcendental meditation contexts include physical discomfort from prolonged holding of certain postures, a sense of detachment from one's body and mental processes, a loss of contact with reality and negative spiritual effects, although rare, such as religious delusions (Shapiro 1992; Lustyk et al. 2009).

In the last one-to-two years there has been an emerging concern about the negative effects of mindfulness in the popular literature and media. This is complicated by the fact that mindfulness has become an umbrella term for a wide array of approaches that may not be 'mindfulness-based interventions' as we understand them in the research literature (van Dam et al. 2018b). For example, Mani et al. (2015) identified that among 500 mindfulness-related smart phone apps in 2015, only 5% were assessed as actually providing mindfulness training and education. Regardless, the research field has responded by encouraging researchers to take a closer look at potential for adverse effects and scrutinising methodological issues in studies of MBIs. In a critical evaluation of the agenda for mindfulness and meditation-based intervention research, van Dam et al. (2018b) states that it is plausible that 5% of people could experience a negative effect from participating in mindfulness-based interventions, similar to the rate common to other psychosocial interventions as cited by Crawford et al. (2016). A mixed method study by Lindahl et al. (2017) explored meditation-related difficulties, challenges and distress among experienced Buddhist meditation practitioners (n=60) and meditation experts (n=32) predominantly in the United States. Through content analysis of interviews, this study identified 59 adverse meditation-related experiences, categorised within seven domains of effect: cognitive, perceptual, affective, somatic, conative, sense of self, and social. The authors identified variable participant interpretations of and reactions to the adverse experiences:

> The associated valence ranged from very positive to very negative, and the associated level of distress and functional impairment ranged from minimal and transient to severe and enduring (Lindahl et al. 2018 p 1).

These findings resonate with those of Shapiro (1992) and Lustyk et al. (2009) discussed previously. Further, Lindahl et al. (2017) identified that 12% of the sample had adverse experiences within 10 days of commencing meditation practice and 25% encountered negative effects whilst practising less than an hour a day. This suggests that people can experience adverse effects early in the process of learning meditation and during relatively short meditation practice sessions. Due to the deliberate sampling of meditators who had experienced negative meditation-related effects, findings may not reflect actual frequency of adverse experiences among Western Buddhist meditators.

Whilst the constructs of 'risk' or 'harm' are not prominent in the mindfulness-based intervention literature, potential contraindications for particular clinical populations, are noted in the literature and suggestions made to safeguard more vulnerable populations. For example, MBIs are regarded to be potentially contraindicated for those with a history of psychosis and schizophrenia, or at least that certain aspects and practices of mindfulness programs will need to be skilfully adapted so that participants are able to manage internal experiences (Dobkin, Irving & Amar 2012; Kuyken, Crane & Williams 2012). It is recommended that pre-screening interviews are conducted with each participant prior to program commencement, to ascertain suitability through provision of further information about the course and gathering information relevant for risk assessment, such as psychiatric problems and suicidality. Pre-screening is also advocated to predict potential problems, such as high levels of avoidance behaviours that might be activated and instigate drop out and to identify alternative, more suitable pathways or additional supports if required (Segal, Williams & Teasdale 2018). In addition, Dobkin, Irving and Amar (2012) emphasises encouraging participants to make empowered choices about their engagement in the

different mindfulness-based practices, depending on their own needs and circumstances and to desist from practice that causes adverse experience.

Within the mindfulness intervention literature, 'challenges' as opposed to 'risk' is the dominant terminology used. Studies have reported that learning mindfulness in the context of a mindfulness-based intervention can be challenging in that it requires significant effort, commitment and time (Laurie and Blandford 2016; Morgan, Simpson & Smith 2015), both during the formal sessions and in the context of home practice (Carmody & Baer 2009; Mackenzie, Poulin, & Seidman-Carlson, 2006). Participants' concern that they are not doing it 'properly' and reported feelings of discomfort in turning towards internal and external experiences, as opposed to avoiding them, have also been reported (Baer and Krietemeyer 2006). However, authors (Cousins & Crane 2016; Mindfulness All-Party Parliamentary Group 2015) have pointed to the potential for short-term challenging experiences to give way to greater benefit if skilful mindfulness instructors are present and create a supportive learning space. The Melbourne Academic Mindfulness Interest Group (2006, p 290) explains: 'the skill of the instructor in dealing with such eventualities may be important in determining whether they become valuable learning opportunities or, alternatively, adverse events.' That said, a wider lens brought to mindfulness research that enquires into and seeks to appreciate the challenges that participants encounter in the learning of mindfulness, as well as the benefits, would seem important.

3.4.4 Qualitative Research on Mindfulness-based Interventions

Whilst not as prominent in the MBI literature, qualitative studies have provided another way of looking into the complex, multifaceted effects of MBIs of what it is like to learn and use mindfulness (Mackenzie et al. 2007). Qualitative mindfulness intervention

research has utilised methods of in-depth interviews, focus groups and review of MBI participant diaries. The populations of interest have included, among others, mental health populations (Lundgren et al. 2018), patients with chronic (Tate, Newbury-Birch & McGeechan 2018) and advanced illness, as well as healthy, non-clinical populations such as students and health professionals (Kerr, Josyula & Littenberg 2011). Meta-syntheses and meta-ethnographies of qualitative mindfulness research provide a useful way of making sense of findings across studies. This synthesised understanding is important, because despite the rich findings elucidated by individual studies, they 'risk being lost as disparate isolated islands of knowledge without some attempt to sum them up' (Sandelowski, Docherty & Emden 1997, p 367). Further, their ability to inform policy and practice becomes diluted (Downe 2008). Three key reviews synthesising the body of qualitative work are outlined here to identify key benefits of MBI participation elucidated by qualitative enquiry.

Malpass et al. (2012), provided a meta-ethnography of 14 qualitative studies reporting patient (n=170) experiences of MBSR and MBCT. Study populations were diverse and included patients with mental health conditions as well as those with chronic health illness. Eleven studies utilised the method of in-depth semi-structured interviews, two used narrative analysis of mindfulness participant diaries and one used focus groups. Malpass and colleagues (2012), identified three temporal phases through which participants progress as they learn and gain benefit from learning mindfulness. The first conceptualised as 'perceived safe certainties' involved exposure to and increased insight into previous coping. In a second phase of 'safe uncertainty' participants acquired a 'steadiness' to look into their experience and learn new ways of relating to that experience. Malpass et al. (2012) drew attention to participants' descriptions of movement in how they perceived and engaged with their experience.

The four processes underpinning this second phase included 1) 'dis-identification and letting go', 2) 'facing the difficulty', 3) 'present focus and focusing in' and 4) 'looking at things more broadly'. The third temporal phase was described as 'grounded flexibility' marked by developing personal expertise or self-efficacy in dealing with experiences, as opposed to feeling helpless. The four therapeutic processes identified as supporting this final phase included 1) 'sense of control and self-regulation', 2) 'acceptance and kindness', 3) 'embodiment and sense of command over the body' and 4) 'taking action and flexible response'. Malpass et al. (2012, p 11) explained that these three phases, underpinned by their different therapeutic processes, culminated in a meta-theme of 'transformation in the relationship to the illness experience and a change in the way they experience themselves'.

Another meta-synthesis of 15 qualitative studies by Wyatt, Harper & Weatherhead (2014) exploring the experience of group MBIs for individuals with mental health difficulties (n= 190), identified eight interacting themes. The first theme, 'prior experience and expectations', described participants' lack of 'core-self' and turning away from difficult experience prior to learning mindfulness. The second theme 'normalising and supporting process of the group', emphasised shared experience, mutual support and acceptance of mental health issues. The third theme, 'relating differently to thoughts and feelings', involved learning to tolerate emotions, slow down and get space from ruminating thoughts. Other themes included 'acceptance' of thoughts, experiences and self; 'a sense of control and choice'; 'relationship with self and others', which described intra-personal and inter-personal 'reunion'; 'struggles', explaining the challenges of finding time to practice, grasping core mindfulness concepts and not doing it right and 'awareness' which described learning to recognise mood states and be less reactionary. All these themes underpinned a meta-theme proposed by Wyatt (2014, p 224) as 'a renegotiation of participants' relationships

with their inner selves and their mental health difficulties'. This finding clearly resonated with earlier findings of Malpass et al. (2012). Both studies, despite the variance in different mindfulness-based approaches and populations, emphasised a change in the way that participants engage with their experience, themselves and others and the value of group processes in aiding this transformation.

Qualitative research has also elucidated benefits of MBIs for professional caregivers, as well as providing insight into some of the challenges in learning mindfulness. A qualitative review and synthesis by Morgan, Simpson and Smith (2015) examined 14 studies of MBCT and MBSR to explore health professionals (n= 254) experience of mindfulness training. Participants included trainees and qualified professionals across the fields of social work, nursing, clinical psychology, occupational therapy and medicine, 84% of whom were female. Morgan and colleagues (2015) identified two main themes: 1) 'health-care workers experiencing and overcoming challenges to mindfulness practice' and 2) 'changing relationship to experience' in personal and interpersonal domains. The first theme detailed participants learning to overcome obstacles to engaging in mindfulness practice such as finding time, feeling restless during mindfulness practice and overcoming a sense of guilt in looking after themselves, when an outward focus on others is more familiar. The second theme of changing relationship to experience in the personal domain detailed a change in the way participants coped with their emotions and how they related to themselves. Like Malpass et al. (2012), Morgan, Simpson and Smith (2015) found descriptions across studies of participants learning to 'step back from' and gain a different perspective on their intrapersonal processes, which aided an increased sense of being able to cope with difficult experiences. In the interpersonal domain, mindfulness training and an increased sense of

'shared humanity' were described as enabling more mindful and empathic interactions with others.

3.4.5 Mechanisms of Change

In comparison to the efficacy studies and descriptive-based research undertaken to explore the effects of mindfulness, research into how and why MBIs have the beneficial effects they do, has received significantly less attention. It is helpful to briefly outline several mechanisms thought to underly therapeutic change, however it is beyond the scope of this thesis to present a detailed analysis of these. Whilst at varied stages of conceptual and empirical exploration, preliminary evidence has identified, among others, the following potential mechanisms of action for MBIs:

- *metacognitive awareness and decentering* (Teasdale et al. 2002), which is described as an ability to observe thoughts and feelings as temporary events in the mind, as opposed to seeing them as fixed truths and becoming 'fused with what we experience' (Dahl, Lutz & Davidson 2015, p 516);
- *reduced use of avoidant coping styles* (Baer, Smith & Allen 2004; Berking et al. 2009; Cousin & Crane 2016; Weinstein, Brown & Ryan 2009);
- *increased mindfulness* (Bergomi, Strohle et al. 2013);
- *increased self-compassion* (Øverup et al. 2017; Segal, Williams & Teasdale 2018; Van der velden et al. 2015; Werner et al. 2012), without which, aversion to difficult experience, rather than engagement would likely result (Kuyken et al. 2010);
- *increased awareness* of habitual, dysfunctional thoughts such as rumination and worry, which have been associated with increased risk of depression (Gu et al. 2015)

- Advances in medical imaging, have further identified that mindfulness may enhance wellbeing through creating *neurophysiological changes* in the brain that relate to emotional regulation, attention and self-awareness, which are implicated structures in a range of mental health difficulties (Acevedo 2016; Davidson et al. 2003; Hölzel et al. 2011a; Tang, Hölzel & Posner et al. 2015).
- A prominent model developed through qualitative inquiry is the '*Re-perceiving Model*', advanced by Shapiro et al. (2006). Re-perceiving is conceptualised as a meta-mechanism of mindfulness, enabling a fundamental shift in perspective. This process of re-perceiving is understood to facilitate four additional mechanisms of action including: 1) self-regulation, 2) values clarification (congruence between action and what is valued), 3) cognitive, emotional, and behavioural flexibility (described as being more aware and adaptive towards one's experience and reactions) and 4) exposure or turning towards difficult experiences to facilitate desensitisation (Baer 2003; Brown, Ryan & Creswell 2007b; Kabat-Zinn 2013; Shapiro et al. 2006). Morgan Simpson and Smith (2015) in their meta-synthesis of 14 MBI studies for health professionals, suggests that reperceiving could be a relevant mechanism of action in the caregiving setting.

Understanding the processes leading to therapeutic change remains an important focus for ongoing research. This will help the refinement of mindfulness-based approaches and guide the selection of participants who may benefit most from accessing mindfulness training (Baer 2003; Brown, Ryan & Creswell 2007a; Murphy et al. 2009; Segal, Williams and Teasdale 2018). Authors have also suggested that MBIs change mechanisms may differ among mindfulness intervention types, levels of mindfulness experience, participant

populations and situations and therefore, the need to consider context is important (Hölzel et al. 2011b; Gu et al. 2015).

In reviewing both the quantitative and qualitative mindfulness-based intervention literature broadly, the evidence suggests that MBIs in their different forms, offer a range of beneficial effects across different clinical and non-clinical populations.

3.5 Mindfulness-based Interventions for Informal Palliative Caregivers

This, the second section of this chapter, provides a systematised review of the application and effects of MBIs specifically for informal palliative caregivers and identifies the remaining gaps and silences in the literature. Additionally, the methodological challenges and limitations of existing mindfulness research in this area will be addressed. Explicit connection will be drawn between the identified gaps in the literature and the focus of this present study.

3.5.1 The Application and Effect of MBIs for Informal Palliative Caregivers

Whilst both quantitative and qualitative research suggest that mindfulness-based interventions may have beneficial application in the setting of professional caregiving, the application and feasibility of MBIs and exploration of their effect for informal caregivers has only recently begun to receive research attention. Emerging research on the effects of mindfulness-based approaches for informal caregivers in the context of disability and chronic health have yielded positive results. Minor et al. 2006 found that informal caregivers of children with chronic disease, following an 8-week MBSR program, had an overall reduction in stress symptoms of 32% ($p < .001$) and in total mood disturbance of 56% ($p < .001$), (Minor et al. 2006). Similarly, Hou et al. (2014), in a study of MBSR for informal

caregivers of adults with chronic conditions, found significantly greater reductions in anxiety post intervention, in depressive symptoms, post and at 3- months follow-up and significantly greater self-efficacy scores at three months post intervention, than the control group. Evidence of positive flow-on-effects from caregiver mindfulness training, to the person for whom care is being provided, is also beginning to emerge. Singh et al. (2004) examined the effects of an eight-week mindfulness program for caregivers of adults with a profound disability and found a significant increase in the level of happiness displayed by care recipients when interacting with a caregiver who received mindfulness training compared to a control care giver (Singh et al. 2004).

These findings of positive effect of MBIs for caregivers caring in the context of disability and chronic illness are suggestive of benefits for informal palliative caregivers. However, the increased sensitivity, complexity and narrow window of engagement in a palliative care context warrant careful evaluation. To this aim, a review of the peer reviewed literature was undertaken to gain a synthesised understanding of the application, effects and feasibility of MBIs for informal palliative caregivers. This work resulted in a published systematic review (Jaffray et al. 2016), as provided in Appendix 2. Additional articles published since that time, have been reviewed and incorporated into a comprehensive synthesis of MBIs for informal palliative caregivers. Reflective of the fact that a meta-analysis is not possible, due to heterogeneous study designs, types of MBIs, caregiver population and study outcomes and in keeping with the qualitative style of this thesis, the review has been constructed and presented here as a narrative review of the literature. Its purpose in this thesis is to synthesise what is known in the literature about the effects of MBIs for informal caregivers and what there is yet to be known. The full search strategy is presented in Appendix 1.

Target studies for inclusion in this review were primary peer reviewed studies, reporting empirical data, on the effects of mindfulness-based interventions[1] for informal palliative caregivers[2].

Description of study design and sample characteristics

As presented in Table 1 (Page 104), this review included 21 studies. All studies were conducted in the last eight years, predominantly in the USA (n=13) in metropolitan settings. Study designs included six randomised controlled trials, one randomised trial, six pre-post and two-wait list, controlled studies. Four studies employed a mixed method research design (Hoppes et al. 2012; Kogler et al.2013b; Stöckle et al. 2016; Van den Hurk et al. 2015). In the case of two studies, there was a level of ambiguity and inconsistency between the authors description of their study type and the research process and methodology described. For example, a study by Cottingham et al. (2018) exploring the effect of a MBI for advanced cancer patients and their caregivers whilst self-described as a qualitative study, was determined on review to be a mixed method study. One study reported the qualitative findings from a larger RCT (Marconi et al. 2016). Of the nine studies using a control condition, four used an equivalent comparison group and one an 'active listening' control group; two employed a wait-list control and two used a treatment as usual control. Across the studies, 30 different outcomes were measured, the most common being depression,

[1] Informal palliative caregivers were defined as someone who provides a caring or support role to a person with a life-limiting, progressive, incurable illness, based on social connection or kinship. Articles focusing on professional care providers or volunteers, employed by an organisation were excluded. Stage of disease was not specified, and illness type was inclusive of both cancer and non-cancer.

[2] A Mindfulness Based Intervention was defined as a program that aimed to teach people, through experiential learning of various meditation practice show to cultivate present moment attention on the changing field of thoughts, feelings and sensations, without judgement. Studies investigating mindfulness as a state or trait, in the absence of a mindfulness intervention were excluded. The intervention also had to be provided directly to the population of interest: informal palliative carers.

anxiety, perceived stress, caregiver burden and mindfulness. Eleven studies employed follow-up measures, ranging between one-and six-months post intervention. Only one study had a longer-term follow-up of a year.

In terms of the informal palliative caregiver samples, studies overall had small sample sizes, with the exception of Fegg et al. (2013) and an associated study by Kogler et al. (2013b), who had sample sizes of 160 and 130 respectively. Across the 21 studies, there were 803 participants. Dementia family caregivers were the most frequently researched population of interest (n=10). Six studies focused on family caregivers of people with advanced cancer, three on informal palliative caregivers (of which, most care recipients had advanced cancer or neurological conditions), one on caregivers of patients with Amyotrophic Lateral Sclerosis (ALS) and one study focused on Multiple Sclerosis (MS) caregivers. Patient–carer dyads were the focus in 11 studies. Caregivers were predominantly female, white, non-Hispanic and caring for spouses or partners. Parents were the second most commonly cared for population. Across studies the age range of participants was 21-98 years, however the majority were aged 50 years and older. Only 11 of the 21 studies reported participant education level. The varied descriptions used across studies to describe level of education made comparisons difficult, however a large percentage of participants in each study had a high level of education. Length of time caregiving was under reported across studies. The reviewed studies are presented below in Table 1.

Table 1: Reviewed studies of mindfulness-based interventions for informal palliative caregivers

AUTHOR, COUNTRY CAREGIVER FOCUS	CARING FOR	STUDY DESIGN	N	GENDER	AGE RANGE / (MEAN AGE)	EDUCATION	ETHNICITY	MBI TYPE / SESSIONS / HOME PRACTICE REQUIREMENT
Controlled Studies								
Oken et al. (2010) **United States** **Dementia caregivers**	Spouse (n=23) Parent (n=8)	RCT *Education Group OR Respite only control*	31	25 Female (80.6%)	45-85 years	N/S	White (n=28) African American (n=1) Asian (n=1)	MBCT Group adapted 7 x weekly 1.5 hr sessions Home practice NS
Franco, Sola & Justo (2010) **Spain** **Dementia caregivers**	Family relationship not specified	Wait-list controlled study	44	31 Female (70.4%)	34-66 years	N/S	N/S	Meditacio'n Fluir: (Elements of MBSR & ACT) 10x Weekly 1.5-2hrs 40 min daily home practice
Whitebird et al. (2013) **United States** **Dementia caregivers**	Parent (n=58) Spouse, sibling or friend (n=20)	RCT *Education Support Group Control*	78	69 Female (88.4%)	32 - 82 years / (56.8 years)	High school / some College n=34 (43.6%); College n=27 (34.6%); Graduate school n= 17 (21.8%).	Non-Hispanic White (n=76)	MBSR Group 8 x weekly 2.5 hr sessions + 5hr retreat Home practice N/S
O'Donnell (2013) **United States** **Neuro-cognitive and dementia caregivers**	Spouse (n=24) Parent (n=4)	RCT *Progressive Muscle Relaxation Group Control*	28	23 Female (82.4%)	66-88 years / (71.6 years)	Some Vocational n=1; Vocational Graduate n= 1; Some College n=6; College Graduate n=10; Master's n=6, Doctoral n=1	N/S	MBSR Group 8 x Weekly 2.5 hours 7.5 hr retreat 45–60 min, 6 days a week home practice.
Norouzi, Golzari & Sohrabi (2014) **Iran** **Dementia caregivers**	Family relationship not specified.	Wait-list controlled study	20	20 Female (100%)	N/S	N/S	N/S	MBCT Group 8 x weekly 1.5 -2.5 hr sessions Home practice NS

AUTHOR, COUNTRY CAREGIVER FOCUS	CARING FOR	STUDY DESIGN	N	GENDER	AGE RANGE / (MEAN AGE)	EDUCATION	ETHNICITY	MBI TYPE / SESSIONS / HOME PRACTICE REQUIREMENT
Fegg et al. (2013) **Germany** **Informal palliative caregivers (82.7% advanced cancer, 12.8% neurological)**	Partner (n=82) Parent (n=35) Child (n=4)	Randomised Trial *TAU Control*	133	93 Female (69.9%)	23-88 years	None or secondary n= 29 (22.7%), Vocational Secondary n=42 (32.8%); Grammar school n=15 (11.7%); University Degree n=42 (32.8%)	N/S	Existential Behaviour Therapy (EBT) Group 2 × half-day sessions on consecutive days, then 4 x weekly-sessions (22-hr total) 5-min × 2 daily home practice
Kogler et al. (2013b) **Germany**	*As above*							
Kogler et al. (2013a) **Germany** **Bereaved informal palliative caregivers**	Partner (n=16)	Qualitative Interviews	16	10 Female (62.5%)	38-78yrs	N/S	N/S	
Brown, Coogle and Wegelin (2016) **United States** **Dementia caregivers**	Spouse (n=16) Parent (n=19) Other (n=3)	RCT *Social support control group*	38	32 Female (84.2%)	39-88 years / (61.14 years)	High school n=1 (2.7%); Graduate training n=11 (29.7%); College n=13 (32.4%); College degree n=13 (35%)	Caucasian 75.7%, African 21.6%, Hispanic 2.7%	MBSR Group adapted Home practice not stated I day retreat 8 x weekly sessions of shorter duration (1.5 - 2 hours)
Beng et al. (2016) **Malaysia** **Informal palliative care patients and caregivers**	N/S	RCT Pilot Study *Active-listening control*	20 Patients (n=9) Caregivers (n=11)	Characteristics of patients and caregivers not reported separately				1 x 5-minute guided mindfulness practice in one to one setting

AUTHOR, COUNTRY CAREGIVER FOCUS	CARING FOR	STUDY DESIGN	N	GENDER	AGE RANGE / (MEAN AGE)	EDUCATION	ETHNICITY	MBI TYPE / SESSIONS / HOME PRACTICE REQUIREMENT
Schellekens et al. (2017) Netherlands **Patients with lung cancer and their caregivers** ***50% palliative, 50% curative***	Partner (n=44)	RCT multicentre parallel design *TAU control*	107 Patients (n=63) Caregivers (n=44)	25 Female (56.8%)	60.8 mean age	Low n=8 Intermediate n=22 High n=14	N/S	MBSR Group 8 x weekly 2.5-hour sessions 6-hour retreat 45-mins daily home practice
Uncontrolled Studies								
Hankin (2009) United States **MS patients & partners**	Partner (n=25)	Pre-Post *No Control*	50 Patients (n=25) Caregivers (n=25)	Characteristics of patients and caregivers not reported separately				MBSR Group 8 x Weekly 2.5-hours, 4.5-hr retreat 45 min formal home practice, 6 days a week
Epstein-Lubow et al. (2011) United States **Dementia / frail elderly caregivers**	Parent (n=7) Spouse (n=2)	Pre-Post *No Control*	9	9 Female (100%)	28-73 years/ (56.2 years)	N/S	Caucasian (n=6), African American (n=3)	MBSR 8 x weekly 75-min sessions 30 min daily home practice
Hoppes et al. (2012) United States **Dementia caregivers**	Parent (n=7) Spouse (n=4)	Pre-Post *No Control*	11	10 Female (90%)	44-81 years/ (63.8 years)	N/S	Caucasian (n=11)	MBSR Group adapted 4 X weekly 1-hr Sessions Home practice NS
Lengacher et al. (2012) United States **Advanced -stage cancer patients and caregivers**	Spouse (n=22)	Pre-Post *No Control*	52 Patients (n=26) Caregivers (n=26)	16 Female (61.5%)	51.5 mean age	High School or less n=7 (26.9 %); Some College n=10 (38.5%); College or Professional Degree n=9 (34.6 %)	White, Non-Hispanic (n=23) 88.5 %	MBSR-C (cancer) 6 x weekly 2-h sessions Group and individual home practice on alternative weeks. 15–45 min daily home practice

AUTHOR, COUNTRY CAREGIVER FOCUS	CARING FOR	STUDY DESIGN	N	GENDER	AGE RANGE / (MEAN AGE)	EDUCATION	ETHNICITY	MBI TYPE / SESSIONS / HOME PRACTICE REQUIREMENT
Ho et al. (2016) **United States** **Alzheimers disease caregivers**	Parent (n=13) Spouse (n=4) Friend (n=1) Grandmother (n=1) Self (n=1)	Prospective single arm intervention trial *No control*	20	19 Female (95%)	39-77 years (60.9%)	N/S	Caucasian (n=16)	MBSR Group adapted 1.5-hours x 8 weekly sessions Home practice with guided CD, time N/S 4-hour retreat
Paller et al. (2015) **United States** **Patients with progressive cognitive decline and their caregivers**	Spouse (n=13) Parents (n=5) Mother-in-law (n=1) Daughter-in-law (n=1)	Pre-post pilot study *No control*	37 Patients (n=17) Caregivers (n= 20)	16 Female (80%)	31-98 years/ (62.5 meant age)	Mean years of education 16.6	N/S	MBSR group adapted (with elements of DBT and ACT) 8 x weekly 1.5hour sessions 30-60 min daily home practice with guided CD
Van den Hurk et al. (2015) **Netherlands** **Advanced lung cancer patients and caregivers**	Partner (n=13)	Mixed Methods Pilot Study 11 Qualitative interviews	32 Patients (n=19) Caregivers (n=13) *n=6pts* *n=5* CGs	9 Female (56%)	30-76 years/ (60.9 mean age)	N/S	N/S	MBSR Group adapted Additional psychoeducation about grief. 8 x weekly 2.5-hour sessions 1 retreat day Guided CD mindfulness home practice 45 min daily
Stöckle et al. (2016) **Germany** **Informal palliative caregivers**	Partner n=10 Close family member n= 4 Friend n=1	Prospective mixed method study *No control*	31 n=15 / 31 Qual Interviews	22 Female (71%)	52.2 -13.6 years	Elementary school 9.7%). Vocational 32.3%, Grammar school 19.4%, University (35.5%)	N/S	2 x 1-hour Individual Existential Behavioural therapy (EBT) sessions 15 min guided CD practice daily
Marconi et al. (2016) **Italy** **ALS patients and caregivers**	N/S	Mixed Methods study	44 Patients (n=26) Caregivers (n=18)	N/S	57.8 mean age	Primary School n=2; High School n=11; University Degree n=5	N/S	MBSR Group 8 x weekly, 2.5-hour sessions, adapted for physical limitations

AUTHOR, COUNTRY CAREGIVER FOCUS	CARING FOR	STUDY DESIGN	N	GENDER	AGE RANGE / (MEAN AGE)	EDUCATION	ETHNICITY	MBI TYPE / SESSIONS / HOME PRACTICE REQUIREMENT
Atreya et al. (2018) **United States** **Colorectal cancer patients and caregivers**	Significant-other (n=13) Child (n=3) Parent (n= 4)	Mixed methods, Single arm pilot study	53 Patients (n=33) Caregivers (n=20)	12 Female (60%)	21-73 years / (51 mean age)	Professional degree n=10 College Graduate n=2 **missing data in demographic survey*	White n=9; Asian n=1; Other n=3; Latino n=1 **missing data in survey*	8-week audio guided mindfulness sessions + study booklet. Practice instructions emailed weekly with an inspirational quote. 15-20 minutes x 5 days practice per week
Kubo et al. (2018) **United States** **Cancer patients and caregivers * *40% stage III or IV cancer***	Spouse/ partner (n=6) Parent (n=2) Friend (n=1)	Mixed methods pilot study *No control*	28 Patients (n=19) Caregivers (n=9)	7 Female (77.8%)	38-73 years / (58.8 mean age)	College graduate n=6; Postgraduate n=3	White n=7; African-American n=1; Asian n=1	Headspace mindfulness program via smart phone app or online 10-20 min daily guided mindfulness practice
Cottingham et al. (2018) **United States** **Advanced cancer patients and family caregivers**	N/S	Mixed method study Semi-structured interviews post intervention, and survey at 4 weeks post intervention	26 Patients (n=13) Caregivers (n=13)	10 Female (76.9%)	56.58 mean age	N/S	White n=9 (69.2%); African American n=2 (15.4%); Asian n=1 (7/7%); American Indian n=1 (7.7%)	The Mindfully Optimizing End-of-Life (MODEL) Care Intervention 12 hours training including: mindfulness practices (based on MBSR), mindful communication skills and information about advance care planning. 6 x weekly 2-hour sessions Home practice N/S

Mindfulness-based Interventions

As shown in Table 1 above, the reviewed studies of mindfulness-based interventions for informal palliative caregivers employed a diverse range of MBIs. Mindfulness-based stress reduction (n=15) was most commonly, followed by mindfulness-based cognitive therapy (n=2), an acceptance and commitment therapy model (n=1), Existential Behaviour Therapy approaches (n=2) and a mindfulness of breathing approach (n=1). Eleven studies provided mindfulness-based interventions to patient and caregiver dyads, with the remaining ten studies engaging informal caregivers only. Sixteen studies used a face-to-face group-based format, with one study delivering a format of alternating weeks of face to face group sessions and home self- study (Lengacher et al. 2012). Two studies (Beng et al. 2016; Stöckle et al. 2016) employed an individual, or one-on-one, mindfulness teaching approach. A further two studies employed an audio guided mindfulness self-study program at home (Atreya et al. 2018; Kubo et al. 2018).

Most mindfulness protocols varied between 4-10 weekly-sessions of variable length (1 to 2.5 hours) and marked by a range of daily home practice requirements (10–45 minutes). One study by Beng et al. (2016) had a brief protocol of one five-minute mindfulness of breathing program. The study by Stöckle et al. (2016) had two sessions of one-hour mindfulness teaching a week apart, as their protocol. Fourteen studies encouraged home practice and seven studies retained the 'retreat day' or 'day-of-silence' that features as part of the MBSR protocol (Brown, Coogle & Wegelin 2016; Hankin 2009; Ho et al. 2016; O'Donnell 2013; Schelleckens et al. 2017; van den Hurk et al. 2015; Whitebird et al. 2013) but duration varied (4–7.5 hours).

Only 10 of the 21 studies reported the facilitator's mindfulness qualifications and established self-practice, with varying degrees of detail and clarity. This is of interest as having recognised qualifications and an established mindfulness practice oneself is identified by the founders of MBSR, and its derivative approaches, as being fundamental to the integrity of the intervention.

Across the studies, average class attendance rates by informal caregivers were reported to be between 73-93%. In terms of the amount of formal mindfulness home practice undertaken by participants, studies overall reported caregivers engaged in significantly less home practice than recommended. Home practice compliance rates were reported between 57-72% during the mindfulness intervention, with a further reduction post intervention. This is also a finding commonly reported in the wider MBI literature (Parsons et al. 2017). One study found that, whilst there was low compliance with the suggested dose of formal practice, participants reported greater informal mindfulness practice (Fegg et al. 2013).

Retention of participants to full outcome measures varied between 50-100%, with study follow-up periods extending from post intervention only, at 2 months, in some cases 4 and 6 months, with one study having a 12-month follow-up period and still reporting a retention rate of 81.48%. The relatively high retention rate found in most of the studies reviewed is an encouraging indication in terms of the feasibility and acceptability of MBI in the setting of informal palliative caregiving and for conducting further research around this topic.

Quantitative findings

In the quantitative studies reviewed, 30 different outcome measures were used to assess the effectiveness of MBIs for informal palliative caregivers (Table 1). Statistically significant results were found for a range of psychological measures, the most consistent being reduced depression and caregiver burden and increased quality of life. This section briefly details the quantitative findings. It should be noted, however, that these results are derived from studies characterised overall as having small, convenience-based samples of caregivers with homogenous characteristics (predominantly female, white Non-Hispanic, caring for partners in urban contexts). Recruiting representative samples is a common methodological challenge in conducting palliative caregiver intervention research (Steinhauser et al. 2006) which impacts the generalisability of results. These challenges are also widely reported by authors conducting mindfulness-based intervention research in other contexts (Goldberg et al. 2017; van Dam et al. 2018a). The following summarises the quantitative findings of effect identified in the studies reviewed.

Depression, quality of life and caregiver burden: Mindfulness-based interventions were found to have a significant effect on reducing depression in nine of the twelve studies measuring for depression (Brown, Coogle & Wegelin 2016; Epstein-Lubow et al. 2011; Fegg et al. 2013; Ho et al. 2016; Kubo et al. 2018; Norouzi, Golzari & Sohrabi 2014; O'Donnell 2013; Paller et al. 2015; Whitebird et al. 2013). Seven studies found this significant effect occurred post intervention, with two studies also finding a significant effect at 1 to 3-months follow-up. One study found a significant effect for depression only emerged at 12-months follow-up (Fegg et al. 2013). A significant effect for quality of life, post intervention, was also found in four of the five studies measuring this outcome (Fegg et al. 2013; Kubo et

al. 2018; Norouzi, Golzari & Sohrabi 2014; Paller et al. 2015), with Fegg et al. (2013) identifying significant effects also at 3 and 12-months follow-up. Seven studies measured caregiver burden, six with dementia caregiver populations and in one study of advanced lung cancer caregivers. Six of the seven studies found a significant effect for reduction in caregiver burden post intervention, with four also finding significant effects at follow-up time points (Franco, Sola & Justo 2010; Hoppes et al. 2012; Norouzi, Golzari & Sohrabi 2014; Van den Hurk et al. 2015). One study, Epstein-Lubow et al. (2011) found a significant effect on caregiver burden, did not emerge until the 4 to 6-months follow-up.

Anxiety, perceived stress and mindfulness: Mindfulness-based intervention effects on caregiver anxiety were mixed, with only three of nine studies measuring this construct finding a significant effect. Two studies found a significant effect for anxiety post intervention: a randomised trial by (Fegg et al. 2013) and a mixed method study by Atreya et al. (2018). One study, a RCT (Whitebird et al. 2013) identified a significant effect for anxiety only emerged at 1 to 3-months follow-up. Seven studies also measured the effect of mindfulness-based interventions on perceived stress, three of whom found a significant effect (Brown, Coogle and Wegelin 2016; Ho et al. 2016; Whitebird et al. 2013). In all three studies dementia caregivers were the population of interest. A significant effect for increased mindfulness was found in two out of seven studies. In the pre-post, uncontrolled study by Ho et al. (2016) of dementia caregivers, this effect emerged post intervention and a randomised trial of caregivers of advanced cancer and neurological patients found a significant effect emerged at 12-months post intervention (Fegg et al. 2013). This may suggest that mindfulness is not the mechanism of action in the setting of informal palliative caregiving or alternatively that it takes longer for an effect to occur.

Other significant outcomes: Significant effects both post intervention and at follow-up were also found for increased peace (Atreya et al. 2018), hope (Hoppes et al. 2012), overall mental health (Whitebird et al. 2013), and decreased psychological distress (Atreya et al. 2018; Kubo et al. 2018). A significant effect for self-efficacy was found post intervention for dementia caregivers, and for tolerating uncertainty in a study of multiple sclerosis patients and caregivers analysed together. Significant effects on reduced tension and anger in a RCT pilot trial of MBSR for dementia caregivers, compared with an equivalent comparison group was found post intervention by Brown, Coogle and Wegelin (2016). One study found a significant effect for pre-loss traumatic grief in a pre-post study exploring the effects of a modified MBSR group program for 20 dementia caregivers (Ho et al. 2016). Significant decreases in reactivity were also found in a study of audio-guided mindfulness sessions for advanced cancer patients and caregivers analysed together (Atreya et al. 2018).

The quantitative studies reviewed, showed that that there was a dilution of effect over time, which has also been identified in other MBI studies across populations (Hurley et al. 2013). In some instances, outcomes identified as having a significant effect post intervention were not significant at follow-up, for example, depression (Epstein-Lubow et al. 2011; Whitebird et al. 2013), quality of life (Nourizi, Golzari & Sohrabi 2014), perceived stress (Whitebird et al. 2013) and anxiety (Fegg et al. 2013). In other studies, where significant effects endured post intervention to further follow-up time points, there was a weakening of effect (Franco, Sola & Justo 2010; Norouzi, Golzari & Sohrabi 2014; Whitebird et al. 2013). This points to the need to explore ways to sustain the beneficial effects realised post intervention. Authors of included articles suggest drop-in mindfulness groups or connection to virtual networks beyond the intervention in order to extend the period of benefit (Epstein-Lubow et al. 2011; O'Donnell 2013; Whitebird et al. 2013).

Qualitative data also supported consideration of ways to assist participants with ongoing mindfulness practice (Kogler et al 2013a). Whilst study findings suggest benefit, the strength of the evidence is weaker than the larger body of mindfulness intervention literature, where there is now robust evidence to support significant effects of MBIs for a variety of psychological and physical health domains (Grossman et al. 2004). The mindfulness-based intervention studies for informal caregivers use small sample sizes and are underpowered, which may have resulted in type II errors and erroneously finding no significant effect or small effects. The weaker effects may also reflect that in the context of caring for a significant other with a terminal illness stress, and frequently distress, increases over the disease course and escalates as death approaches (Dumont et al. 2006). Therefore, there may not be the magnitude of reduction in psychological and physical health symptoms identified in other settings and may not be realistic under such circumstances. Alternatively, studies may not be measuring the right constructs in the context of informal palliative caregiving.

Qualitative Findings

Most of the studies undertaken to explore the effects of mindfulness-based interventions for informal palliative caregivers have been quantitative. Eight studies incorporating a qualitative approach to enquiry were identified (Atreya et al. 2018; Cottingham et al. 2018; Hoppes et al. 2012; Kogler et al. 2013b; Kubo et al. 2018; Marconi et al. 2016; Stöckle et al. 2016; Van den Hurk et al. 2015). This has resulted in a limited in-depth qualitative understanding of the benefits of MBIs from the experience of caregivers themselves. The following section reviews what is understood about the experience of

mindfulness in end-of-life caregiving, as identified in each of the eight mixed method studies identified.

Hoppes et al. (2012), as part of their mixed method, parallel design study interviewed eight dementia caregivers one month following their participation in an adapted low dose MBSR protocol (4 weekly-group sessions of 1-hour duration). Four key themes related to participant experience of the interventions' effects were identified: 'increased acceptance' of both the care recipient illness, as well as enhanced acceptance / less judgement of self and family; 'increased sense of presence'; 'increased sense of peace and reduced stress'; 'decreased reactivity', particularly in terms of response to difficult care recipient behaviour.

Van den Hurk et al. (2015) conducted semi-structured qualitative interviews with lung cancer patients (n=19) and their partners (n=16) within one year of participating in a group MBSR program. Findings pointed to mindfulness transforming the way that lung cancer patients and their partners engaged with their experiences. The process of change was described as entailing the following sub themes: 'standing still' (taking time for self, leading to inner calm and rest); 'being aware' of thoughts, feelings and physical sensations previously un-noticed; 'insight' into their experience and reactions; 'letting go' of future worries and fears; 'changing behaviour' or making choices more in line with their values and 'acceptance.'

Marconi et al. (2016) also used semi-structured interviews to elicit the experience of 26 patients with Amyotrophic lateral sclerosis (ALS) and their caregivers (n=18) following group MBSR, as part of an ongoing RCT. Grounded theory analysis identified two overarching themes of 'Resources' and 'Limitations'. The theme of resources reported eight

subthemes including ‘improvement in wellbeing’, ‘relaxation’, ‘emotional self-regulation’, ‘acceptance’, ‘consciousness’ (being aware in the present moment), ‘enhanced breathing’, ‘better sleep’, and ‘improved relationships’. The three limitation subthemes included ‘transportation issues and lack of time’, ‘concern about caregiver burden ‘which related to patients’ concern of burdening their caregiver to transport and support their access to the MBSR group and ‘home practice of mindfulness’ which related to illness symptoms, cognitive strain and distraction. Again, the study did not separate caregiver and patient findings, except to point out that caregivers’ most commonly cited benefits included relaxation or promotion of a calm state, enhanced consciousness, ability to be in the present moment and acceptance.

Kogler et al. (2013a) undertook semi-structured interviews with 16 former caregivers of palliative patients, 12 months following participation in a group program of Existential Behaviour Therapy (EBT) in a randomised trial (Fegg et al. 2013). Mindfulness was described as the core element of the intervention and the protocol consisted of 6 weekly-group sessions with 22 hours in total. Interviews explored the helpful aspects of the EBT intervention during the first year of bereavement. Following content analysis, two main categories of benefit regarding EBT during the grieving process were identified: ‘social support’ and ‘self-regulation’. The theme of ‘social support’ encompassed the benefit of interacting with other carers also grieving the loss of a significant other from a palliative illness. The other main theme of perceived benefit of the EBT intervention was ‘self-regulation’, which identified the coping strategies caregivers employed to deal with difficult experiences without becoming overwhelmed. The key subthemes of ‘self-regulation’ included ‘mindfulness and acceptance’, defined as being aware of and accepting current experience. Permitting emotions and stopping rumination were identified as distinct

features of the mindfulness category of self-regulation and helpful in the context of bereavement. Another sub theme of 'self-regulation' was 'focusing on the positive', which included positive evaluation of dying, remembering pleasant experiences and searching for sources of strength. The final sub theme of self-regulation was 'orientation towards new goals' which was made up of conscious activities, living on one's own and taking care of oneself.

Stöckle et al. (2016), reported on a pilot study of individual-based sessions of Existential Behaviour Therapy involving mindfulness offered over two sequential weeks of an hour's duration. The first session was embedded in mindfulness training, with the second moving to enhance resourcefulness through identifying a symbol or artefact bespeaking strength. The authors interviewed 15 informal caregivers of palliative inpatients 4 weeks after undertaking the intervention. Data was analysed via content analysis. Positive effects described by the authors included participants feeling inwardly strengthened in difficult situations through focusing on the breath and present moment experience. Other positive effects included mindfulness offering a tool to gain inner calm and peace of mind and to manage difficulty, along with self-reported improvements in sleep, concentration, awareness, gratitude, energy levels and physical complaints. Challenges included difficulty focusing on mindfulness practice due to busy schedules or when 'worries took over' and needing more support to deepen mindfulness practice and address other individual issues.

Two more recent mixed method studies have explored delivering MBIs as self-study programs utilising audio-guided mindfulness sessions, over an 8-week period at home. The first by *Atreya at al. (2018)* was a MBI study of 33 metastatic colorectal cancer patients and 20 caregivers who learnt mindfulness by listening to 15-20 minutes of daily guided

mindfulness exercises via an MP3 player. A three-month follow-up survey post the intervention, identified that 71% of caregivers reported benefit from learning mindfulness whilst caregiving (Atreya et al. 2018). Additionally, semi-structured interviews pre and post intervention identified benefits including: increased sense of relaxation and calm, a readjustment in attitude and ability to contain thoughts, reduced stress and anxiety, improved focus and concentration and ability to be kinder to self (Atreya et al., 2018). Flexibility of MBI delivery was also identified as a benefit by patients and caregiver alike. Barriers to full participation included busy lives and family obligations, difficulty using the technology and keeping the device charged. Of note in this study, was the use of consumer engagement to support the design and evaluation of the intervention. Two focus groups, one for patients and one for caregivers, conducted prior to the study, elicited participant views about important intervention elements, as well as potential benefits, challenges and barriers to full participation. This is the only example of user engagement in intervention design and evaluation which has been identified in the review of the MBI literature in the setting of end-of-life caregiving.

The second more recent study by *Kubo et al. (2018),* utilising technology assisted MBI delivery, employed a mixed method pilot study design. The population of interest consisted of 19 cancer patients, 40% of whom had stage III or IV cancer, and 9 caregivers. Structured phone interviews were undertaken following an 8-week audio guided mindfulness program studied by participants at home. Seventy-seven percent of caregivers were reported as finding the program either extremely (35%) or very (44%) useful. Some of the benefits included: having a useful tool to combat stress, an increased ability to stay in the present, a lessening of catastrophising, increased calmness, acceptance and refrain from judgement. However, the difference between patient and caregiver data were not easily

discernible. The biggest challenges experienced by caregivers in undertaking the program fully were increasing caregiving responsibilities. Of interest to note, caregivers completing the intervention, had a higher baseline of anxiety and fatigue, than non-completing caregivers. This may suggest the importance of motivation and unmet needs as underpinning factors of caregiver engagement and retention in mindfulness training.

Cottingham et al. (2018) in a mixed method study design, developed and trialled a group mindfulness program for 13 advanced cancer patients and their caregivers. As opposed to specifically targeting enhancement of caregiver health and wellbeing, the intervention, 'The Mindfully Optimizing Delivery of End-of-Life (MODEL) Care intervention', sought to address resistance of patients and caregivers to engage in advance care planning. The intervention was designed to cultivate a greater capacity to encounter and respond to challenging experiences. The intervention involved 12-hours of experiential training in mindfulness practice and mindful communication and the receipt of advance care planning information, offered over 2-hour sessions across 6 weeks. Recruited through their oncology service patients and caregivers engaged in separate audio recorded, semi-structured interviews at 1 and 4 four-weeks post intervention. Whilst describing the interviews as semi-structured, the study reported having only one open ended question at the one-week post intervention time frame, and three open ended questions at the four-week post intervention interview. This suggests that the interview method may be best described as structured interviews or survey. Four themes of benefit, shared by both patients and caregivers, were identified. These included: 'enhanced adaptive coping practices', 'lowered emotional reactivity or being able to engage to choose an intentional response to emotional stimuli', 'strengthened relationships' and 'improved communication' or ability to converse

about sensitive topics such as prognosis, end of life preferences or future fears not previously discussed.

In terms of findings of negative effects of learning mindfulness in end-of-life caregiving, only one study reported negative consequences. A mixed method study of an eight-week audio guided mindfulness program for advanced cancer patients and caregivers, reported participant guilt related to undertaking less mindfulness practice than recommended, concern about 'not doing it properly' and concern that they did not understand the process (Atreya et al. 2018).

Overall, qualitative findings have described a range of intra-personal benefits such as increased awareness, self-acceptance, self-regulation, increased relaxation, and behavioural change in line with values. Interpersonal benefits included decreased judgement, reactivity, and improved relationships). In addition, from the studies reviewed, MBIs appear to enable caregivers to engage with difficult experiences in a more accepting way. Mutual support, shared understanding and self-disclosure were regarded as benefits particularly associated with learning mindfulness in a group context.

Whilst the reviewed studies incorporating a qualitative component of enquiry offer value in beginning to address the lack of qualitative understanding of the impact and experience of mindfulness training in informal palliative caregiving, methodological limitations were noted. The most significant limitation was the underreporting of data collection and analysis processes. All studies fell short of demonstrating reflexivity and due consideration of the relationship between researchers and participants, regarded as a key feature of study quality in the Critical Appraisal Skills Programme (CASP) 'Checklist for Qualitative Studies' (2014); Dixon Woods et al. 2007). The non-separation of patient and

caregiver data and findings also makes it difficult to determine the similarities or differences between caregiver experience, and the experience of the person for whom they are caring. This could serve to further entrench the commonly reported caregiver perception of being invisible or viewed as an extension of the patient, as opposed to being seen as a person in one's own right. In addition, in-depth studies exploring caregiver preferences, experience and meaning making of learning mindfulness in end-of-life caregiving, particularly studies that offer a theoretical or conceptual understanding, are also lacking.

3.5.2 Gaps in the Reviewed Literature

In comparison to the larger body of research investigating the effects of mindfulness-based interventions for patient populations, which extends over 40 years and increases exponentially each year, the application and evaluation of mindfulness-based interventions in the setting of informal palliative caregiving is a relatively new field of inquiry. This review identified only 21 studies, all of which have been published in the last 8 years. Drawing definitive conclusions from the small number of studies identified in this review is difficult, due to small sample sizes, diverse interventions, variable study designs and use of disparate measures. However, findings suggest that mindfulness-based interventions are feasible and acceptable to offer in the context of informal palliative caregiving, based on interview data and recruitment and retention rates. In addition, MBIs may offer benefit for informal caregivers, particularly in terms of reducing depression, caregiver burden and increasing quality of life. Qualitative inquiry, although limited in number and depth, reports benefits of MBIs relating to intra-personal and inter-personal domains, enhanced acceptance of difficult experience and the value of group mindfulness as providing shared understanding. However, three significant gaps in the literature persist. These are briefly discussed below.

1) In-depth Understanding of Caregivers Lived Experience of MBIs

The first gap is that existing understanding of MBIs for informal palliative caregivers' rests heavily on quantitative research. A small number of mixed method studies (n=5) have provided qualitative glimpses into the effects of mindfulness in this context. However, rich, in-depth and conceptual understanding of the process and lived-experience of mindfulness whilst caring for a significant other at the end of life is absent in the literature. Further, the outcomes of MBIs in this setting, regarded as important by caregivers themselves, have not been explored. These outcomes may be very different to those pre-supposed as beneficial and targeted for measurement by researchers and clinicians without appreciating the unique contextual influences of encountering grief, death and dying in end-of-life caregiving. Without this in-depth understanding, research may fail to capture important intervention effects (Oken et al. 2010). Qualitative studies are particularly well suited to exploring complex experiences such as learning and using mindfulness which 'may lead to the development of new, not yet considered categories of psychological effects associated with mindfulness training' (Chiesa 2013, p 265). This more nuanced understanding could subsequently inform more sensitive outcome measures in MBI research (Carmody et al. 2009; Coffey, Hartman & Fredrickson 2010; Dobkin 2008)

More nuanced qualitative understanding could also support conceptual model development regarding the effects and experience of MBIs in the specific setting of informal palliative caregiving, which to date is another unexplored area of research. Beyond identifying outcomes valued by caregivers themselves, there is also a need to explore what these benefits 'mean' to caregivers in the context of end-of-life caregiving.

2) Adverse Effects of MBIs for Informal Palliative Caregivers

The second gap in the literature is a need to bring a more focused lens to explore the potential for adverse effects of MBIs for caregivers. Such consequences may come to the surface if more open, exploratory and in-depth research designs are used, as opposed to focusing on only one facet of experience: beneficial outcomes. This would engender a broader understanding of the effects of participating in mindfulness-based programs, particularly in vulnerable populations. This understanding could also guide program development and mitigate potential adverse effects, by helping participants predict and navigate challenges in participation.

3) Considerations for MBIs for Caregivers in the Context of more Rapidly Progressing Disease

The third evident gap in the literature is a limited understanding of what it is like to learn mindfulness whilst caring for those with rapidly escalating needs within a deficit of time, such as advanced Cancer and Motor Neuron Disease. Much of existing knowledge rests on dementia caregiver populations which have a longer disease trajectory. Understanding of the important considerations when developing and offering MBIs in this end-of-life context, particularly from caregivers themselves, is lacking. Questions remain in terms of the best format, mode of delivery and timing for offering MBIs as well as other important elements that might underpin sensitive and conducive engagement of end-of-life caregivers in mindfulness training. This void in the literature maintains the position of caregivers being 'in the shadows' (Andershed & Ternestedt 2001; Linderholm & Friedrichsen 2010; Grande et al. 2009), limits innovation and impedes program development and

delivery in a way that is feasible and acceptable to caregivers within the constraints and difficult logistics of caregiving.

Seeking the experience and perspectives of mindfulness facilitators, who have provided MBIs for informal caregivers, may also add to understanding what key considerations may best drive the development and offering of MBIs in the setting of end-of-life caregiving, compared to other client populations. As yet, mindfulness facilitator experience and perspectives on this topic have not been explored in the empirical literature.

3.5.3 Methodological Limitations of the Reviewed Studies

Mindfulness intervention research for informal palliative caregivers shares the same methodological challenges and limitations of the wider MBI literature across other populations, and arguably, is very similar to the broader informal palliative caregiver literature, previously discussed in Chapter Two. These include

- small, underpowered sample sizes (Baer 2003; Chiesa & Serretti 2011);
- lack of longitudinal studies (Baer 2003; Hofmann et al. 2010);
- underreporting of intervention compliance, number of participants lost to follow-up and associated reasons (Parsons et al. 2017);
- underreporting of sampling and recruitment methods; and
- poor description of participant characteristics.

Drawing definitive conclusions of the efficacy of MBIs for informal palliative caregivers, is difficult, due the diversity of mindfulness interventions and protocols, participant populations, study designs, outcome measures and underlying methodological limitations (Shonin, van Gordon & Griffiths 2013). The use of wait-list controls, as opposed

to active control groups to account for effects such as facilitator attention and group processes is also a noted limitation in the literature (Baer 2003; Fjorback et al. 2011; van Dam et al. 2018b). Studies have also been criticised for ill-defining the multi-faceted and complex constructs under investigation (Davidson & Kaszniak 2015) and providing inadequate detail of intervention content. Description of mindfulness facilitator training and whether facilitators had a self-practice of mindfulness, are also under-reported, which is significant in that these two factors are considered fundamental to the intervention fidelity in the traditional MBSR and MBCT programs (Baer 2003; Ledesma & Kumano 2009). More detailed reporting of sampling and recruitment methods, as well as participant characteristics, particularly level of education and ethnicity, are also required.

One specific limitation to informal caregiver mindfulness-based intervention research is the predominant practice of recruiting convenience-based caregiver samples. Most of the existing evidence rests on the experience of caregivers who are recruited through and already connected to supportive and palliative care services. This creates a problem in terms of representative sampling on two fronts. Firstly, as discussed in Chapter Two, samples drawn in this way will be skewed towards caregivers who are already in receipt of support, which will have shaped their caregiving experience in different ways to those caregivers who are not connected to services. Secondly, because convenience samples are often recruited into research by health professionals who have judged them as resilient or stable enough to participate in the study, caregivers who are more distressed or vulnerable will be unlikely to have been provided with an opportunity to participate in MBI research. As a result, there is limited understanding of how more vulnerable or distressed caregivers encounter mindfulness training, the challenges they face, or their perception of what mindfulness-based approaches may need to look like in this setting to facilitate

caregiver access and retention. Whilst not clearly stated across all studies, much of the MBIs for caregiver research appears to have been conducted in large metropolitan areas. Therefore, there is a need to consider the experience and key considerations of carers accessing and participating in MBIs in rural contexts, as it is likely that they will face unique challenges due to a dispersed geography and reduced resources. Efforts to recruit more male caregivers, caregivers with lower level of education and caregivers from more diverse ethnic origin are also required in MBI caregiver research. This is also an issue in the broader MBI research.

Whilst quantitative research makes up the largest body of work in the mindfulness intervention research literature, there is a strong argument for more qualitative work to be undertaken in the field to advance more nuanced understanding of effect and what this means to people in their lives (Chiesa, Anselmi & Serretti 2014; Smith et al. 2005). To enhance the rigour and trustworthiness of findings, qualitative studies of mindfulness-based interventions for informal caregivers are encouraged to provide more detailed reporting of sampling methods, as well as the processes of data collection and analysis. Greater reflexivity in considering and making explicit the relationship between the researcher and study participants and moving beyond purely describing experience to offering theoretical and conceptual models that advance understandings of MBI's effects, are also required.

3.6 Chapter Summary

This chapter has introduced mindfulness, its ancient foundation in Buddhism and further application as mindfulness-based interventions, across diverse settings, to alleviate suffering and support holistic health and wellbeing. In reviewing the broader mindfulness-based intervention literature, MBIs were found to offer a range of positive psychological and

in some cases, physical health benefits for diverse clinical and non-clinical populations. Qualitative findings suggest that MBIs have a transformative effect on the way that participants perceive and relate to themselves, others and difficult life events.

The review of the peer-reviewed literature of the application, effects and feasibility of mindfulness-based interventions for informal palliative caregivers, whilst an early field of enquiry, suggests that MBIs are feasible and acceptable to offer to informal palliative caregivers and may provide benefit particularly in terms of reducing depression, and caregiver burden and increasing quality of life. No adverse outcomes have been reported. Most of this evidence is founded on quantitative studies of dementia caregiving populations. A small number of mixed method studies have provided qualitative glimpses into the beneficial effects. However, there remains a need for more in-depth, rigorous qualitative studies to get at the heart of the experience of learning and using mindfulness in the context of end-of-life caregiving and what value or meaning this has for the caregivers who have lived this experience. There is also more to be known about the challenges faced by caregivers learning mindfulness, the potential for adverse effects, as well as the key considerations for developing and offering MBIs in the intense and complex space of informal palliative caregiving. This understanding is critical to guiding what, when and how to deliver mindfulness-based approaches for caregivers to maximise benefit and mitigate adverse effect. There is also a requirement for more conceptual model development to aid a more sophisticated understanding of the experience of learning and using a mindfulness-based approach, particularly as an informal palliative caregiver, caring in the more advanced stages of disease.

The thesis now moves to Part III, consisting of one chapter: 'Research Design and Methodology'. This chapter will present the research questions and detail the design, methodology and research methods used to answer them, making transparent the process of data collection, analysis and theory development.

PART III: STUDY METHODOLOGY

Part III of the thesis comprises only one chapter: Chapter 4, 'Research Design and Methodology'. Building on the background chapters in Part II, this part of the thesis introduces the aims and questions of this present study in relation to the gaps identified in the literature. It also explains the qualitative approach and constructivist grounded theory methodology adopted as the strategy of inquiry and details the study design and methods, including a comprehensive account of the cycles of data generation and analysis.

The overall aim of Part III is to provide a defensible view into the research process and its guiding methodology and philosophical assumptions. It attends to issues of rigour and trustworthiness, as well as the important ethical considerations in end-of-life caregiving research.

CHAPTER 4

RESEARCH DESIGN AND METHODOLOGY

4.1 Chapter Introduction

As established in the previous chapters, there are significant gaps, both in research and in practice, regarding support interventions for informal palliative caregivers. There is an imperative need for self-care interventions which extend beyond practical and information-based support designed to enhance patient care. Interventions that recast a focus on the wellbeing of caregivers, as persons in their own right are strongly indicated. Mindfulness-based interventions have demonstrated potential as a holistic, self-care approach. However, the lack of qualitative studies in this area has limited current understanding of potential challenges and adverse effects, along with knowing how best to offer mindfulness-based interventions in the complex end-of-life caregiving setting.

This chapter outlines the design and methodology of this study. It articulates the research aims and questions before justifying the adoption of a qualitative approach and a constructivist grounded theory methodology. The chapter details the overall study design, research setting, participant recruitment and sample characteristics. It also explicates the data generation and analysis methods used in this study and outlines the ethical considerations in conducting research in the setting of end-of-life caregiving.

4.2 Research Aims and Questions

This study sought to explore, in a rich and detailed way, what it is like for informal caregivers to learn and use mindfulness during end-of-life caregiving. The key aim of this research was to:

> *To provide an in-depth, conceptual understanding of the experience of learning and using a mindfulness-based approach whilst caring for a family member or friend at the end of life*.

The focus of this study was to explore potential value and benefit, but also risk and adverse effects associated with the experience of mindfulness-based approaches in end-of-life caregiving. An understanding of the key elements of providing mindfulness training to informal palliative caregivers was also sought to guide informed development and implementation of MBIs in this setting. In consideration of these aims, this study was initially guided by two main research questions:

1. *How is learning and using a mindfulness-based approach in the context of end-of-life caregiving experienced and described, including potential for value and benefit, as well as adverse effects and harm?*

2. *What are the key considerations in developing and providing mindfulness-based approaches for informal palliative caregivers and why are they important?*

One additional question, which became important to the developing theory, arose during data collection and analysis. This is consistent with a grounded theory approach which advocates that data drives further data collection and analysis. This question was:

3. How do informal palliative caregivers engage with the concept and practice of considering and taking care of themselves and their own needs?

4.3 Research Approach and Methodology

This section outlines and justifies the qualitative research approach chosen in this study. It presents the key philosophical and methodological underpinnings of the research and how these guided the design and the conduct of this study.

4.3.1 A Qualitative Approach

A qualitative approach is a key accepted tradition within social and health research (Bryman 2017; Creswell 2013; Holloway 2005; Liamputtong 2013; Lincoln & Denzin 2005; Mason 2002). Patton (2015, p 56) describes qualitative research in the following way:

> Qualitative inquiry means going into the field - into the real world of programs, organisations, neighbourhoods, street corners and getting close enough to the people and circumstances there to capture what is happening... The qualitative emphasis on striving for depth of understanding, in context, includes capturing inner perspectives.

Qualitative research is well suited to investigating complex behaviour, perceptions and experiences that are poorly understood or cannot be easily quantified, such as the experience of dying and bereavement (Creswell 2013; Greenhalgh 2010). Within the field of health, a qualitative approach can also generate rich understanding of how people experience health interventions (France et al. 2015), or help uncover effective components of complex interventions, where these have been uncertain (Campbell et al. 2000; Coates 2004; Gülmezoglu et al. 2013; Morse, Penrod & Hupcey 2000). Such understanding,

grounded in lived experience, has served to inform the design and delivery of programs in many social and health-care sectors, that are more likely to be effective in real practice settings (France et al. 2015; Sandelowski 2004). As such, qualitative research has been increasingly used within the fields of palliative care and bereavement (Koenig, Back & Crawley 2003; Payne & Turner 2008; Williams 2016). Adopting an interpretive orientation, qualitative research pursues detailed, in-depth exploration of the 'qualities' of social phenomena as experienced and made sense of by individuals who have encountered them (Bazeley 2013, p 3). This approach contrasts significantly with the focus in quantitative research of seeking quantification of the incidence, properties or cause and effect of the studied phenomenon (Lincoln & Denzin 2005).

Qualitative research, regarded as 'a field' of social enquiry (Coates 2004, p 329), encompasses a variety of approaches, born from diverse disciplines such as anthropology, philosophy and sociology. It has been further shaped by divergent thinking within these fields and through application in different contexts such as psychology, education and health (Avis 2005). Despite the diversity of approaches, there are some common characteristics and philosophical positions which are broadly agreed to underpin qualitative research and which distinguish it from quantitative research (Green & Thorogood 2014; Creswell 2013). Whilst not wanting to rigidly dichotomise or revive the 'paradigm wars' between qualitative and quantitative research, contrasts between their philosophical and methodological approaches can be usefully drawn (Bryman 2012).

4.3.2 Qualitative Philosophical Assumptions and Methodologies

Creswell (2013), outlines different underlying philosophical assumptions between qualitative and quantitative research regarding ontology, epistemology, axiology and

methodology. Each of these will now be briefly discussed to establish why a qualitative approach was congruent with the aims of this present study.

Ontology and Epistemology

Ontology refers to the philosophical assumptions 'about the nature of social reality' (Hesse-Biber & Leavy 2010, p 4). Within qualitative research inquiry there is clear recognition 'of many ways of knowing' (Hartman 1994, p 459). This study assumes an interpretive or relativist ontology of multiple, subjective realities as perceived and experienced by different individuals that may change over time (Bryman 2008). This can be contrasted to the objectivist or positivist ontological position of quantitative research of a fixed, single, objective reality.

Qualitative and quantitative approaches also have different epistemologies which can be defined as philosophical beliefs about 'what counts as knowledge and how knowledge claims are justified' (Creswell 2013, p 20). Patton (2015) explains that adopting, what sociologist Max Weber termed 'Verstehen', which is defined as a humanistic, empathic and relational approach in qualitative research, is critical. Access to participants' perspectives, knowledge and sense making of their world, is founded on the qualitative researcher engaging with individuals in natural, real-life settings (Lincoln & Denzin 2005). This is in comparison to quantitative positivist approaches whereby the researcher maintains distance from and objectifies participants as objects only to be studied (Creswell 2013; Green & Thorogood 2014).

This study takes the epistemological position that knowledge resides within the subjective, lived experience of caregivers, and that their experiences of caregiving can be elicited only through 'first person reports and narratives' (Drisko 2016, p 310). A qualitative

approach was most suited to this study because it would assist in gaining an emic perspective or 'insider view' (Holloway & Galvin 2016, p 6) of the experience of learning and using a mindfulness-based approach whilst caring for a family member or friend at the end of life. It would enable this, by drawing on multiple viewpoints of informal palliative caregivers and those who have provided mindfulness training in end-of-life caregiving to generate 'thick descriptions' (Geertz 1973). Only a qualitative approach could facilitate 'Verstehen' through the empathetic understanding of the private and often emotional caregiver experiences within this study. This chapter will demonstrate how the research approach and methods utilised in this study supported the development of trust between the researcher and participants to gain this in-depth understanding.

Axiology and Methodology

Qualitative and quantitative research also differ regarding axiology: the philosophical view of the role that values play in the research process (Creswell 2013, p 21). In contrast to the objectivist position of quantitative research, qualitative research adopts the axiological view that research cannot claim to be a value-free endeavour (Liamputtong 2013). In this view, both the researcher and the participant are 'of the world' in which research takes place and their values and perceptions, shaped by context, are regarded to inherently frame how they see the world. This philosophical position was adopted in this study, taking the view of Green and Thorogood, that 'there is no privileged place we can occupy from which to study the world objectively' (2014, p 23). Consequently, in keeping with the qualitative tradition, a strong commitment to researcher reflexivity was adopted throughout the research. Reflexivity is a critical feature of rigorous qualitative research (Mason 2002; Patton 2015), described as the ongoing process of researchers reflecting on their research practice,

decision-making and analysis. This includes using the same critical and rigorous lens applied to the research topic, to examine and mitigate one's own assumptions biasing the research process (Creswell 2013; Green & Thorogood 2014). Later parts of this chapter will address how researcher reflexivity was employed in this study.

Qualitative and quantitative research also have differing methodological philosophies. To generate deep understandings of what it might be like to learn and use mindfulness in end-of-life caregiving, an emergent, flexible study design was indicated (Avis 2005). Emergent, flexible study designs advocate against highly prescribed, fixed research procedures and plans, in preference of being open to the changing dynamics and new learning that emerge through the research process (Hesse-Biber & Leavy 2010). A flexible and emergent approach is a key methodological characteristic of qualitative research (Creswell 2013) and supports the potential for research questions and methods to change in response to emerging data (Holloway 2005). A further point of difference in methodological philosophy is that qualitative research regards contextualisation as important, whereas quantitative research pursues generalisation of findings across wider populations. Emphasis is placed, in qualitative research, on locating participants' experience, actions, interactions and sense-making in the context of their everyday lives and more broadly in respect to economic, political and cultural contexts (Holloway & Galvin 2016). Mason (2002) asserts that the strength of qualitative research is in its ability to offer more complex, holistic and contextual understandings of the social world:

> Qualitative research celebrates richness, depth, nuance, context, multidimensionality and complexity…Instead of editing these elements out in search of the general picture or the average, qualitative research factors them directly into

its analyses and explanations. This means that it has an unrivalled capacity to constitute compelling arguments about how things work in particular contexts (p 1).

4.3.3 Constructivist Grounded Theory as the Strategy of Inquiry

A qualitative grounded theory research approach was regarded as highly congruent with this study's aims. Furthermore, the central tenets of this constructivist methodology resonated with the philosophical worldview of the researcher, offering a way to preserve the voices of caregiver participants within a conceptual rendering of their experience. The following section outlines the aims, brief history and central characteristics of grounded theory methodology, followed by a discussion of the divergent elements of Charmaz's (2006) constructivist adaption, which is the approach adopted in this study.

Overview of Grounded theory

Grounded theory was developed by the German sociologists, Barney Glaser and Anselm Strauss, in 1967. During their research collaboration on terminal illness and dying hospital patients in 1965, entitled 'Awareness of Dying', they developed the 'constant comparative method', which would become known as the grounded theory method. Since this time, grounded theory has been recognised as a systematic research methodology employed in the health and social sciences, to examine and explain processes and interactions in the social world (Charmaz 2006, Creswell 2013).

Grounded theory was heavily influenced by the theoretical paradigm of symbolic interactionism, informed by the seminal work of Mead (1934) and Blumer (1966). Symbolic interactionism was concerned with understanding how social interactions, behaviour, sense of self and the roles that individuals adopt, are influenced by the context in which they

occur (Patton 2015). Specifically, there was a focus on the meanings that individuals attribute to symbols (actions, events, language) within a shared culture through socialisation processes and how these change over time (Holloway 2005).

The intent of grounded theory is the generation of rich, interpretive understanding or theoretical accounts of social phenomenon grounded in the studied data (Glaser & Strauss 1967; Charmaz 2006). In advocating that theory of the social world be grounded in rigorously collected and analysed data, grounded theory significantly challenged the sociological theory practices of the time which were undertaken by scholars and 'appointed elites', frequently in the absence of empirical research (Charmaz 2008b). Further, in providing the first systematic guiding framework for conducting qualitative research, grounded theory helped to establish and legitimise qualitative research as an approach, at a time when quantitative methods had begun to be considered as the only rigorous and truly 'verifiable' field of research within social inquiry (Strauss & Corbin 1994; Glaser & Strauss 1967).

Strauss and Glaser's 'Awareness of Dying' (1965) research established the utility of grounded theory within many domains of social and health research and fittingly in palliative care itself. In constructing an in-depth theoretical account of the relationships between nurses and their terminally ill patients, mediated by different levels of death awareness, Strauss and Glaser demonstrated the significant possibilities in a shift from the more common descriptive outcomes of qualitative research to one which held value in theorising complex social processes and experiences such as caregiving, illness and death (Padgett 2012; Liamputtong 2013).

Grounded theory has since emerged as one of the most widely known and adopted qualitative research approaches, particularly well-suited to exploring topics that are poorly understood and lack theory (Glaser & Strauss 1967; Holloway 2005). Over the last decade there has been an increase in the number of grounded theory studies undertaken in the chronic health, palliative and bereavement research settings (de la Cuesta-Benjumean et al. 2012; Duggleby et al. 2010; Holtslander, Bally & Steeves 2011; Kita & Ito 2013; Mehta et al. 2010; Penrod et al. 2012), particularly in the discipline of nursing (Bluff 2005; Lazenbatt & Elliot 2005). Within this present study, grounded theory provides an ideal approach to explore and generate a theoretical understanding of the experience of mindfulness-based interventions in end-of-life caregiving, where there are significant gaps in knowledge, understanding and evidence.

The Evolution of Grounded theory

The grounded theory method as developed by Glaser and Strauss and which endures today, is underpinned by a core set of characteristics (da Silva Barreto, Garcia-Vivar & Marcon 2018). These characteristics, identified by Charmaz 2006; Creswell 2013; Liamputtong 2013, include the following:

- Generation of theory, as opposed to descriptive accounts of experience;
- Adoption by the researcher of an 'openness' to emerging data as opposed to allowing preconceived ideas and theoretical constructs to drive analysis;
- An iterative and simultaneous process of data collection and analysis whereby the emerging theoretical concepts inform subsequent data collection and analysis;
- Use of 'theoretical sampling' involving the selection of participants based on their ability to test the emerging theory, until reaching theoretical saturation;

- Systematic data analysis progressing through at least three different and increasingly abstracted coding cycles, using the method of constant comparison;
- Analytic memo-writing to document emerging understanding of the data, including the evolution of codes and conceptual categories, their properties and relationships to each other, as well as reflections on the research process; and
- Development of a theoretical or conceptual model that identifies and accounts for the interrelationship between key concepts in order to explain the process under study.

Like most research traditions, grounded theory has evolved through various renderings of the approach, different proponents and changing worldviews. This evolution was catalysed initially due to a major disagreement between Glaser and Strauss in which Strauss came to reject some of the more traditional, objectivist approaches advanced by Glaser, particularly the inductive and deductive processes of data analysis. For example, Strauss came to disagree with Glaser's emphasis on data existing in and of itself, ready for 'discovery' with a view that it 'relied on direct and often, narrow empiricism' (Charmaz 2006, p 8). Strauss further questioned an over-reliance on constant comparison methods. In preference, he adopted new technical procedures and coding cycles to identify and conceptualise the emergent theory. In doing so, Strauss (1987) adapted the grounded theory methodology and in a subsequent collaboration with Janet Corbin (Strauss & Corbin 1990), took grounded theory in the direction of greater explication of methods, underpinned by a move towards pragmatism. Pragmatism is a widely accepted paradigm, particularly within mixed methods research that takes the view that 'knowledge is both constructed and based on the reality of the world in which we live and in which we

experience' (Liamputtong 2013, p 460). Pragmatism, therefore, emphasised grounded theory researchers employing methods that would best answer the research question.

More recently, post-modernist adaptions of grounded theory have been developed including dimensional analysis (Schatzman 1991), situational analysis (Clarke 2005) and constructivist (Charmaz 2006). Whilst Glaser remains resistant to the evolution and remodelling of grounded theory, many have welcomed the adapted variants of the methodology (Bryant & Charmaz 2007; Charmaz 2006, Mills, Bonner & Francis 2006b; Strauss & Corbin 1990). Such ontological and epistemological shifts have enabled the expression of grounded theory in different and creative ways in the service of generating interpretive understanding. However, it is recognised by many authors (Charmaz 2006; Dixon-Woods, Booth & Sutton 2007) that within the research literature, a significant number of studies have misrepresented themselves as grounded theory studies, when adherence to central elements of the methodology have been absent (Becker 1993; Lazenbatt & Elliot 2005; Hutchinson & Wilson 2001).

4.3.4 Constructivist Grounded Theory

This study adopted the constructivist grounded theory approach developed by Kathy Charmaz (2006). Charmaz's approach continues to embody the central tenets of grounded theory as previously articulated, including an open approach, simultaneous data collection and analysis, embedded cycles of coding and constant comparison, memo-writing and sampling for theory development. However, its underpinning constructivist worldview gives rise to several divergent elements to both Glaser and Strauss's (1967) traditional version and Strauss and Corbin's approach (1990).

Firstly, constructivist grounded theory (CGT) assumes the existence of multiple, socially constructed realities, as opposed to Glaser and Strauss' (1967) traditional grounded theory assumption of a single, objective reality that can be 'discovered' (Charmaz 2006). The researcher's role in constructivist grounded theory is not one of a distant, neutral observer or 'excavator' of facts. Instead the researcher is positioned as an active part of an interactional process, wherein both the participant and the researcher co-construct knowledge as issues are explored and reflected on (Creswell 2013, Liamputtong 2013). In adopting this subjective epistemological position, traditional grounded theory notions of a value free inquiry are refuted. Instead, Charmaz argues that 'researchers are not passive receptacles into which data are poured' (2006, p 15). Constructivist grounded theory asserts that the fundamental issue is for researchers to adopt a rigorous, reflexive practice to explicitly identify their prior experience, values, and assumptions and examine their influence on the research process (Charmaz 2008b).

Secondly, constructivist grounded theory's intention to provide rich, interpretive understanding of the studied experience in the contexts in which they occur, including the larger cultural, social and historical contexts, is another point of difference from Glaser and Strauss' (1967) traditional grounded theory methodology (Mills, Bonner and Francis 2006a). Charmaz (2008a, p 402) asserts:

> Instead of aiming to achieve parsimonious explanations and generalisations devoid of context, constructivists aim for an interpretive understanding of the studied phenomenon that accounts for context.

Thirdly, the rendering of data in analysis and the presentation of the theoretical outcome in constructivist grounded theory further diverges from that of Glaser and Strauss

(1967) and Strauss and Corbin (1990). Constructivist grounded theory often adopts a more literary style of writing which retains thick description and embeds theory into the narrative (Charmaz 2006). There is also an explicit concern to preserve participants' presence, voice and meanings, both during analysis and in the presentation of the analytic outcome. Authors such as Mills, Bonner and Francis (2006b, p 32) assert that skilfulness on behalf of the researcher is required 'to resolve the tension between developing a conceptual analysis of participants' stories and still creating a sense of their presence in the text'. Constructivist grounded theory, however, does emphasise a return to traditional grounded theory's emphasis on placing the examination of actions and processes as central concerns in analysis.

Finally, Charmaz's constructivist grounded theory approach diverges significantly from Strauss and Corbin's (1990) explication of analytic processes. In Charmaz's view grounded theory methods are perceived as 'a set of principles and practices, not as prescriptions or packages' (2006, p 9). This view favours the adoption of the key characteristics of grounded theory (previously described) in flexible, inductive and creative ways, as opposed to being fixed and bound by strict methodological rules or recipes (Charmaz 2006, p 9).

Constructivist grounded theory was determined to be the most appropriate methodology for this study for three key reasons. Firstly, reflective of the key aims of this study, it is fundamentally concerned with the generation of interpretive, theoretical understanding of experience, not just description. Secondly, it holds as a principal focus, the examination and explanation of the 'process' of learning and using mindfulness in the context of end-of-life caregiving. Thirdly, it emphasises preserving the presence and voice of

participants throughout analysis and in the final theoretical outcome. This position reflects a critical concern in this study not to contribute to the invisibility of caregivers, but to amplify their voice and experience in the service of developing theoretical insights in the experience of learning and using a mindfulness-based approach in end-of-life caregiving and what models may need to look like in this setting. Furthermore, the underpinning constructivist philosophies of multiple, socially constructed realities, the generation of understanding and meaning through interaction and the positionality of the researcher in the co-construction of knowledge resonated strongly with the researcher's own worldviews and professional background as a social worker.

4.4 Study Design and Methods

This section provides an overview of how the study was designed and conducted, followed by a detailed description of each core activity. This section is structured into six key parts: (1) study overview, (2) ethical considerations of conducting end-of-life caregiving research, (3) the research setting, (4) sampling procedures, (5) recruitment strategy, and (6) overview of the research participants. The methods of data generation and analysis, being larger sections are presented in detail at sections 4.5 and 4.6.

4.4.1 Study Overview

The exploratory, qualitative aims of this study necessitated recruiting participants most able to offer nuanced insight into the experience of learning and using a mindfulness-based approach whilst caring at the end of life. Mindfulness facilitators, with experience of offering MBIs for informal palliative caregivers, were determined as the first source of data. It was anticipated that facilitators could reflect on the experiences of different caregivers

learning mindfulness in this setting. Further, they could contrast these with what they had observed in other populations for whom they had provided mindfulness training. Additionally, mindfulness facilitators would be most suitably placed to provide insight into the best method of providing MBIs in the end-of-life caregiving setting and whether this diverged from that provided in other contexts.

Underpinned by emerging findings of a need to gain more nuanced understanding of the 'lived experience' and constructed meaning of learning and using mindfulness whilst caring at the end of life, and to further test and examine emerging concepts and theory, informal palliative caregivers constituted a second, critical source of data in this study. It was anticipated that caregivers could also offer a first-hand account of the elements they regarded as important in developing and evaluating MBIs in this setting.

For clarity in reporting the methods used in this study, two phases are referred to. Phase One refers to research undertaken and involving mindfulness facilitators, who were recruited and interviewed first. Phase Two refers to the research involving informal palliative caregivers who were recruited and interviewed following Phase One. It is important to acknowledge that while these two stages occurred separately, there was a high level of flow and interconnectivity between them. This reflects the constructivist grounded theory constant comparison and theoretical sampling methods used in cycles of data collection and analysis.

The visual depiction, provided in Figure 2 on the next page, outlines the key steps involved in this present study consistent with a constructivist grounded theory design. The first part of the diagram depicts the undertaking of a literature review to guide the formulation of this study's aims and questions and identifies the chosen research approach

and methodology previously discussed. The second half of the diagram depicts the key research activities undertaken, as they relate to each phase, with the ensuing sections of this chapter to explain each aspect in detail.

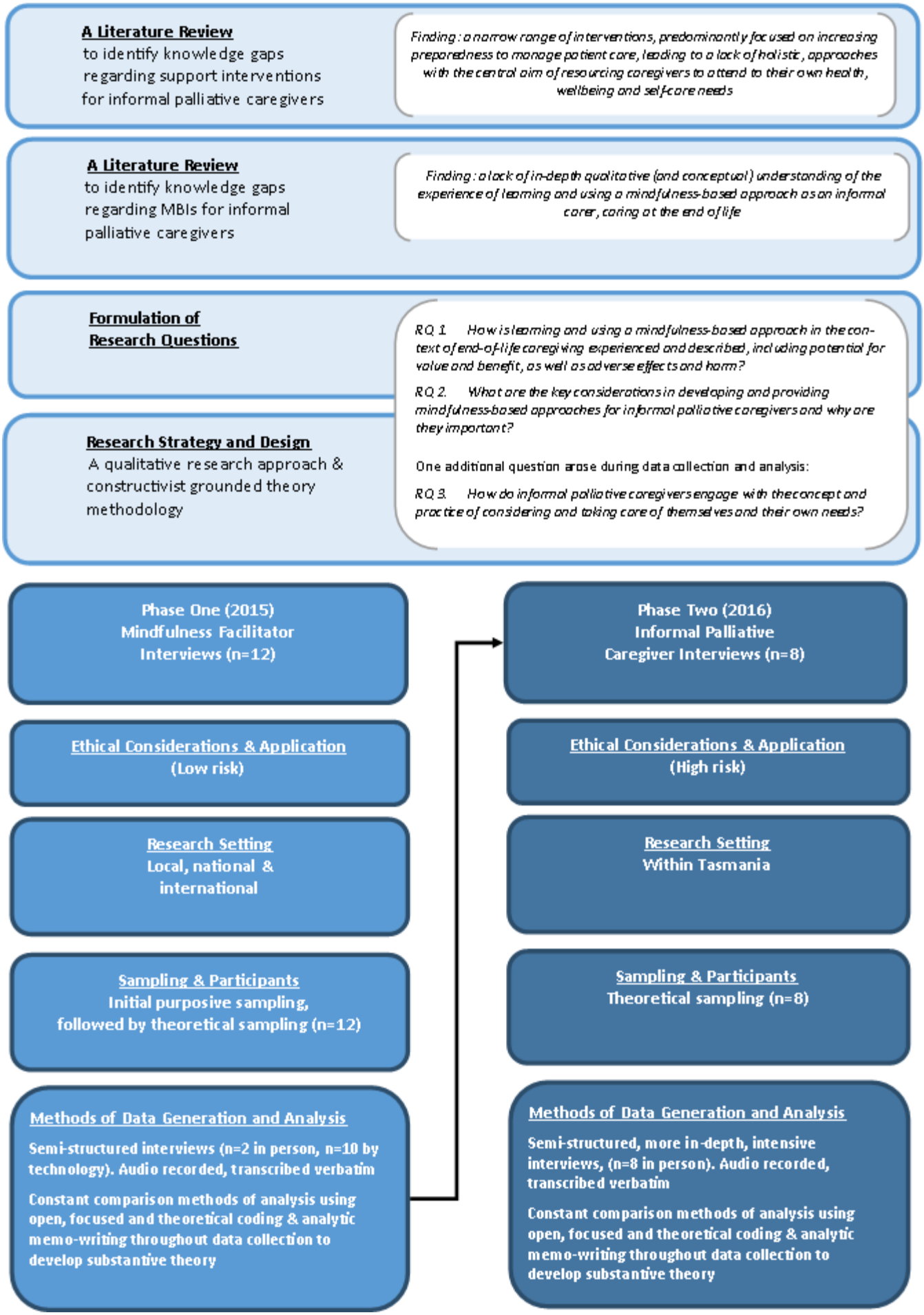


Figure 2: Overview of the Research Process in this Study

4.4.2 Ethical Considerations

Conducting research in the setting of end-of-life caregiving requires careful ethical consideration and associated choices of design and methods so as not to further burden caregivers through participation in research (Higginson et al. 2013; Hudson 2013). Prior to confirming the study's methodological approach, literature was reviewed to understand the ethical issues common to end-of-life caregiving research. This is reflected in the placement of ethical considerations depicted in Figure 2. Three overarching ethical issues were identified and helped to inform the design and conduct of this study: (1) the consequence of assuming caregivers are too vulnerable to participate in research, (2) considerations of how to reduce power differentials between the researcher and participants, and (3) managing the tension between obtaining knowledge and ensuring participant care and safety. Each of these will now be briefly discussed.

As discussed in Chapter Two, the literature on end of life research ethics is characterised by debates and tensions (Payne & Field 2004; Duke & Bennett 2010; Gysels, Evans & Higginson 2012). Informal palliative caregivers are often regarded in research, as they are in practice, as an 'at risk' or vulnerable population, due to the sensitive and intense experiences associated with end-of-life caregiving and bereavement (Renzetti & Lee 1993). De Raeve (1994), for example, advocates strongly that research within the setting of end of life is unethical, with a view that patients and caregivers are too vulnerable for research participation. There are equally strong opposing views (Aoun et al. 2017; Berry 2004; Casarett et al. 2005; Fine 2003; Gysels, Evans & Higginson 2012) that regard it as unethical not to provide caregivers with the choice to participate in research. Such authors have identified a range of consequences which they perceive result from a binary perception of

caregivers as 'vulnerable'. The first is that caregivers are not a homogeneous group, and that labelling all caregivers as vulnerable 'disrespects their personhood' (Berry 2004). Further, if caregivers are perceived as 'too vulnerable' they may be excluded or not invited to participate in research: a practice referred to as 'gatekeeping' (Aoun & Nekolaichuk 2014; Hudson, Aranda & Kristjanson 2004). Gatekeeping can result in biased knowledge or a skewed picture away from caregivers with higher needs and greater levels of distress (Duke & Bennett, 2010; Harding et al. 2012).

Another increasing argument in the literature, and the one adopted in this study, is that the practice of denying caregiver choice and self-determination regarding research participation is paternalistic (Aoun et al. 2017; Gysels, Evans & Higginson 2012; Iphofen 2005; Koenig, Back & Crawley 2003). Guidelines for ethical palliative care and end of life research certainly advocate strongly for allowing autonomous decision-making of patients and caregivers regarding their participation in research to avoid limiting their participation through inappropriate gatekeeping and paternalistic attitudes (Gysels et al. 2013, p 914). Studies have established that informal caregivers are capable of deciding whether to participate in research (Gysels, Shipman & Higginson 2008a) and should be allowed to exercise self-determination regarding study participation (Bentley & O'Connor 2015). Further, studies have found that many caregivers receive benefit from doing so (Hudson 2003b; Johnston et al. 2012; Koffman et al. 2012; Pessin et al. 2008; White & Hardy 2010). Benefits reported include experiencing research as cathartic or therapeutic (Germain, Mayland & Jack 2016), personal gains, such as the acquisition of insight into their experience (Aoun et al. 2017), feeling acknowledged, listened to and validated (Crowther & Lloyd-Williams 2012; Gysels, Shipman and Higginson 2008b; Hudson 2003a) contributing towards service development (Gysels, Shipman & Higginson 2008a) and helping others in a similar

situation (Aoun et al. 2017; Germain, Mayland & Jack 2016). Further, the recruitment of caregiver voices and collaboration in research is considered critical to the development of effective interventions that are acceptable to and feasible for caregivers to access (Grande et al. 2009; Steinhauser et al. 2006). For all the reasons outlined above, caregiver participation in this present study was highly valued and sought to best understand the lived experience and knowledge of caregivers in the endeavour of understanding the experience of MBIs in end-of-life caregiving.

This research did, however, strongly situate responsibility with the researcher to acknowledge the sensitivity and complexity of the palliative caregiving setting, to manage perceived risks, appreciate the methodological challenges and to employ a carefully considered design and supportive process (Gysels, Evans and Higginson 2012).

This study was conducted with a critical awareness that all research involves a level of power asymmetry between the researcher and the research participants (Brinkmannn & Kvale 2015; Taylor 2005) because 'allowing a researcher into one's life for study may itself imply a loss of power' (Iphofen 2005, p 26). Further, the researcher sets the research questions and the focus of the interview and in the process of obtaining knowledge will 'research into private lives and place an account of them in the public arena' (Birch et al. 2012, p 1). Attending to these power imbalances is important in all qualitative research (Brinkmannn & Kvale 2015; Creswell 2013; Taylor 2005), underpinned by regular and ongoing reflexivity on behalf of the researcher (Creswell 2013; Taylor 2005). However, it is heightened when researching sensitive topics such as end of life, death and bereavement and for populations like informal palliative caregivers who already experience a level of disempowerment in relation to the events happening around them, their engagement with

health services and their inability to control the outcome of their significant other's terminal illness (Hughes 2015).

This study attended to the asymmetry in power relations through the following accepted activities of ethical research. These included (1) ensuring participants received detailed information about the interview process (Green & Thorogood 2014), (2) offering participants choice in terms of time, date and location of interview (Birch & Miller 2002; Crowther & Lloyd-Williams 2012), (3) allowing the opportunity to take a break or stop the interview at any time (Brinkmann & Kvale 2015), (4) assuring confidentiality (Creswell 2013), (5) explaining the dissemination of research findings (Iphofen 2005), and (6) positioning the researcher in relation to the study (Charmaz 2006). These activities are more fully described in the forthcoming section which details the methods of data generation.

Managing the tension between seeking nuanced participant accounts of mindfulness in end-of-life caregiving in the pursuit of knowledge, and ensuring participant care and safety was also considered. Brinkmannn and Kvale explain that qualitative research 'requires a delicate balance between the interviewer's concern for pursuing interesting knowledge and ethical respect for the integrity of the interview subject' (2015 p 84). Activities of this study directed toward enhancing participant care and safety extended from the beginning phases of design, through data collection and analysis, to writing the grounded theory and the dissemination of findings. They included: (1) writing a detailed protocol around managing potential participant upset, (2) considering the skilfulness and experience of the researcher to support participants should they become emotional or distressed, (3) the provision of post interview debriefing and or connection to support services, and (4) careful thought regarding the presentation of data to preserve anonymity and the integrity of

participants and their data. These ethical considerations are integrated and more fully discussed in the data generation and analysis sections of this chapter.

Ethical Approval to Conduct the Study

Ethical approval for this study proceeded in two phases. In Phase One, prior to the interviews of mindfulness facilitators, a 'low-risk' ethics application was submitted to and approved (H0014541) by the University of Tasmania's Health and Medical Research Ethics Committee (Appendix 3). A low-risk ethics application was considered appropriate, based on the view, that issues of grief, death and loss may arise as they pertain to the observed experiences of others. However, these issues would be familiar to participants within their everyday work and unlikely to cause significant personal upset or distress.

In contrast, a high-risk ethics application was submitted for Phase Two of the study: interviewing informal palliative caregivers themselves. It was considered that by inquiring into caregivers' personal caregiving and bereavement experiences, upset could be triggered, due to the sensitive and emotional nature of these topics. Ethics approval was received by the University of Tasmania's Social Science Human Research Ethics Committee (Reference number H00145513 and is provided in Appendix 4).

4.4.3 The Research Setting

It is important to acknowledge the influence of the research setting on the choice and application of study methods. Understanding the research setting also aids consideration of study findings in relation to the context in which they were generated. Within this study, the varied settings between Phase One and Phase Two shaped the study methods and procedures in different ways. These phases are now described.

Phase One – Mindfulness Facilitators

Phase One of the study engaged a broad range of mindfulness facilitators across diverse geographical locations including both nationally within Australia and internationally. The inclusion of such broad settings was based on the view that MBIs are more established at a national and international level, enabling access to participants with greater experience of offering MBI for informal palliative caregivers and a larger sample size, than if only targeting mindfulness facilitators within the small population of Tasmania.

The research settings in Phase One included diverse workplaces, such a carers' organisations, cancer centres, palliative care services, bereavement services, mindfulness organisations and private practices, as well as academic health settings. These extended across four different states of Australia (Tasmania, Victoria, New South Wales and Queensland) as well as international settings including the United Kingdom, the United States of America, and Malaysia.

Phase Two - Informal Palliative Caregivers

In terms of the research setting in Phase Two of this study, all caregiver interviews were conducted in-person within Tasmania, at a place preferred by participants. This was based on an ethical concern to be physically present with caregivers and better able to support them as they shared what was anticipated to be sensitive and personal experiences of learning and using mindfulness in end-of-life caregiving and bereavement.

Tasmania is a small island state in Australia with a population of 509,965 people (ABS, 2016). Under the Australian Standard Geographic Classification – Remoteness Areas (ASGC-RA), all of Tasmania is considered regional or remote, including the capital city, Hobart (ABS 2018). Despite the smaller population compared to other states and territories

in Australia, there is a higher burden of chronic disease. For example, in 2014, people in Tasmania were more likely to have a long-term health condition (67%) than other states and territories in Australia (ABS 2014). Tasmania, also, is the most ageing state in Australia, with people aged 65 years and over making up 19.4% of the population (ABS 2017). Compared to the national average, median personal incomes in Tasmania are 13.4% lower (Eslake 2017) and access to specialist health services more difficult (Public Health Information Development Unit 2017).

Tasmania is characterised as having geographically dispersed communities, which is one factor underpinning the difficulty of accessing health care in the state. For example, there are only two main specialist health centres, one in the North and one in the South, requiring travel by patients and families in more rural and remote areas to access specialist treatment. With respect to palliative support services, there is only one designated hospice facility which is situated in the capital city, Hobart, in the south of the state. Tasmanians living in the north of the state travel between 2 -2.5 hours one-way to access this service, with north west residents having to negotiate over 4 hours one-way through a more difficult geography. The tyranny of distance often involves a temporary relocation for families. The north and north west regions of Tasmania have a small number, only two or three, designated palliative care beds within hospital acute care wards. Each region of the state has access to community palliative care services, with admission to hospital or aged care instigated for respite, complex symptom management or end-of-life care when community resources have been exhausted. The rural caregiver population in this present study is important, for as discussed in the literature review of Chapter Two, much of what we understand about informal palliative caregiving and the experience of caregiver support

interventions specifically, is based predominantly on qualitative data from metropolitan participants.

4.4.4 Sampling

This section presents the methods of sampling used in this study. Specifically, it identifies and justifies the sampling strategy and inclusion criteria as they relate to each phase of this study. Consistent with a grounded theory methodology, purposive sampling was adopted in the beginning phase of this study (Cutcliffe 2000; Holloway 2005), before progressing to theoretical sampling to test and elaborate emerging theoretical concepts.

Phase One

A purposive sampling strategy was initially used to identify and recruit mindfulness facilitator participants in Phase One. Purposive sampling is a commonly used strategy in qualitative research which aims to identify information-rich samples with experience of the studied phenomenon, so that in-depth description of the issues under examination can be elicited (Patton 2015, p 265). As data generation and analysis proceeded, it became apparent that when facilitators (n=4) spoke of their own experience of mindfulness and end-of-life caregiving, more detailed, vivid descriptions were offered, resulting in the emergence of more dynamic concepts and categories. This finding confirmed the need for subsequent data collection through Phase Two of the study, including the recruitment of participants with direct experience of mindfulness-based interventions in end-of-life caregiving, to further examine the emerging data categories.

Phase Two

A theoretical sampling strategy was used in Phase Two of this study to identify and recruit informal palliative caregivers. Theoretical sampling, a key characteristic of constructivist grounded theory (Charmaz 2006), as outlined previously, is a practice of sampling individuals on theoretical grounds to elaborate on and test the emerging theory or conceptual ideas generated from the data, as opposed to having a predetermined sample (Strauss & Corbin, 1998). Guided by the intended aim of conceptual theory, researchers have the choice between narrow or wider sampling to elaborate and test emerging theoretical constructs (Glaser & Strauss 1967). As the focus of this study was to develop a 'substantive theory' (applicable to one substantive group) as opposed to a formal theory (applicable across wider groups and contexts), a narrower substantive sample who had the most experience in the studied phenomenon was pursued (informal palliative caregivers who had learnt or used mindfulness in the context of caregiving). Sampling was continued until the point of 'theoretical saturation' or the point at which no new ideas or variances to the categories emerged from the data (Charmaz 2006, p 113; Glaser & Strauss 1967).

Participant Inclusion Criteria

The criteria for participant inclusion in this study were slightly different in the two phases of this study, as detailed in Table 2 below.

Table 2: Participant Inclusion Criteria Phase One and Two

Participant Inclusion Criteria	
Phase One - Mindfulness Facilitators	**Phase Two – Informal Palliative Caregivers**
• 18 years or older; • able to give informed consent; • able to speak fluent English; and • had worked with informal caregivers[1] of a significant other in receipt of palliative care services or in the last 12 months of life[2] using a mindfulness based approach[3].	• 18 years or older; • able to provide informed consent; • able to speak fluent English[1]; • living in Tasmania, Australia; • were currently /or had previously been an informal caregiver[2] for a significant other in receipt of palliative care services[3] or in the last 12 months of life; and • were currently / or had previously participated in a mindfulness-based program[4].

[1]*Regrettably, financial resources for interpreters and translators were outside the scope of this thesis*

[2] *An informal caregiver was defined as someone who provides for the emotional, physical or practical support needs of a family member or friend in an unpaid capacity, usually from the basis of kinship or social connection.*

[3]*The criteria of the care recipient receiving palliative care services or last twelve months of life was designed to capture people who had an advancing disease with a relatively short life-expectancy i.e.; less than 12 months, rather than the longer-term degenerative diseases.*

[4] *A mindfulness approach / program was defined as a facilitated program, delivered in a number of sessions over time, that aims to teach participants through meditation practice, how to cultivate attention on the present moment and observe the constantly changing field of thoughts, feelings and sensations without judging or seeking to alter the experience. (See 'Glossary of terms' for more comprehensive definition)*

4.4.5 Recruitment Strategy

The recruitment process across each phase of this study, whilst sharing some similarities, differed on a number of important aspects outlined below.

Phase One- Mindfulness facilitators

Recruitment for the mindfulness facilitator interviews in Phase One of the study occurred between February and December 2015. This study was promoted locally within Tasmania, nationally and internationally, with the view that MBIs in the health sector are more established at the national and international levels. Email contact was made with eight different mindfulness institutes and organisations, four private mental health practitioners and two wellness centres who advertised online, as providing mindfulness training (Appendix 5). Organisations in the hospice and palliative care sector and associated health services were also contacted regarding the study. Nine hospice and palliative care organisations, three carer support associations, five cancer care and one grief and bereavement service were emailed inviting participation (Appendix 5). Professional associations such as the Australian Psychology Association (APA) and local social work professional networks, were also contacted by email. The organisations were asked to disseminate study information to their members, with the aim of capturing mindfulness facilitators who may teach mindfulness across different settings, including those in private practice. Two palliative care online information networks (CareSearch and ehospice) and one international mindfulness-based intervention research network (Web Community Science Corner) were additional sources contacted via email, with a request to post study information. The study was promoted using a one-page plain language flyer which outlined the study and its aims and provided the contact details of the researcher (Appendix 6). A request was made for the study information to be disseminated among the various networks.

From the 37 email contacts inviting study participation in Phase One of the study, 15 mindfulness facilitators responded and expressed interest in study participation. At this point study eligibility was determined and further participant information provided verbally and then forwarded in written form (Appendix 7). Three participants subsequently withdrew prior to interview due to existing work commitments.

In total, 12 mindfulness facilitators expressed an interest to continue participating in the research and met the criteria for study inclusion. Of these, nine had received study information via an email invitation from the researcher, two through a newsletter email posted by an associated professional body and one as the result of snowballing recruitment: that is, receiving information about the study from another participant interviewed in this study.

Prior to interview, all participants were provided with a consent form (Appendix 8) either electronically or via post. In instances where interviews would be conducted by phone or Skype, participants signed and returned a scanned copy of their consent to the researcher prior to interview. The facilitators participating in face-to-face interviews (n=2) signed the consent form in the presence of the researcher just before undertaking their interview.

Phase Two- Informal Palliative Caregivers

In contrast to the strategy in Phase One, (mindfulness facilitators), which extended recruitment to national and international sources, recruitment of participants in Phase Two of this study was limited to informal palliative caregivers living in Tasmania. Recruitment occurred between February and September 2016. In total, 33 different recruitment sources were contacted in this phase to promote the study (Appendix 9).

Similar to Phase One, phone or email contact was made with a range of mindfulness providers within Tasmania (n=5) who had advertised the provision of mindfulness training via the internet. The aims of the study were explained along with a request for providers to display or disseminate study information to caregivers who may want to participate. Study information was presented as a one-page invitation, written in plain language (See Appendix 10) and provided to agreeable providers to pass on to interested participants. All five sources indicated passing on information to others either by providing a printed copy of the flyer or posting the information online via websites, discussion boards and newsletters. This strategy was also used to reach informal palliative caregivers connected to the palliative care sector and caregiver associations (n=20). Sources included an in-patient hospice facility (n=1), an acute hospital facility with palliative beds (n=1), community-based palliative care services (n=5), hospice volunteer agencies (n=2), a grass-roots palliative support group (n=1), carer support associations (n=3), an oncology service (n=1), cancer support organisations (n=3), a community health service (n=1), a health promotion network consisting of multi-disciplines and multi-agencies(n=1) and a state association and advocacy group for hospice and palliative care (n=1).

Additionally, flyers were posted in two community libraries (n=2) and an alternative health centre (n=1). Professional associations such as the Australian Psychology Association (APA) and local social work professional networks were emailed and asked to disseminate study information to members who provide mindfulness training to caregivers and who had indicated a willingness to pass on information to eligible participants. Finally, three mindfulness facilitators, who participated in the first phase of the study and indicated a willingness to support recruitment of informal caregivers, were contacted to pass study information onto potential participants. Care was taken to brief the providers on the

appropriate procedures for sharing study information, including the emphasis of voluntary participation and non-consequence to the services or support that carers, or their significant other, were receiving. Providers were given an information sheet to send out to potential participants.

Caregivers interested in study participation were offered the choice to either make direct contact with the researcher or to pass on their contact details via the provider. At the point of first contact with potential participants the researcher provided study information verbally and then forwarded this information in written form via post or email (Appendix 11). This method of enlisting the support of stakeholders, who are known to and trusted by informal palliative caregivers, has been found to be a successful way of recruiting family caregivers in palliative care research (Fegg et al. 2013; Whitebird et al. 2011). However, as previously stated, it was important in this study not to rely on participant recruitment through specialist services due to ethical issues related to 'gatekeeping' and skewing the sample in the direction of less-distressed caregivers. For this reason, multiple sources of recruitment were pursued.

From 33 different service providers or organisations contacted to display or pass on study information to interested participants, 12 caregivers contacted the researcher to express interest in participating in the study. Nine of these were the result of study information being posted in newsletters or flyers distributed within organisations or professional associations with which they were connected. Two were recruited via their health provider having been provided an information sheet about the study and one participant was recruited through encouragement from a friend who had seen the study advertised in her workplace. Two caregivers did not meet the inclusion criteria of having

learnt mindfulness and were therefore not eligible for study participation. Two caregivers withdrew from the study prior to interview due to changed circumstances. Eight caregivers met the inclusion criteria to engage in this study phase. Written consent was obtained just prior to the interview in the presence of the researcher (Appendix 12). There were no existing relationships between the researcher or any of the research participants.

In total, there were 20 participants recruited for this study. This included 12 mindfulness facilitators and 8 informal palliative caregivers. Interviews with these participants yielded a large amount of rich and complex data that was considered appropriately nuanced to enable theoretical saturation or the testing of the emergent grounded theory. No further recruitment was needed to expand the sample once saturation was reached. This study's sample size is consistent with the methodology of grounded theory, which commonly suggests that sample sizes of between 20 -30 can yield theoretical saturation (Creswell 2013). This study's sample and the data saturation achieved, is also consistent with sampling in qualitative research more broadly. Rather than imposing a fixed sample size to generate meaning and understanding of social phenomena, qualitative research advocates sampling until reaching a rich understanding of social phenomena and the point at which no new themes emerge (Charmaz 2006).

4.4.6 The Study Participants

This section introduces the 20 research participants interviewed in this study. The characteristics and attributes of each are described by each phase.

Phase One – Participant Characteristics

The key characteristics of the mindfulness facilitators interviewed in this study are provided in Table 3 below. These include: gender, country of residence, occupation, work setting, type of mindfulness and format of mindfulness-based intervention delivered.

Table 3: Characteristics of Phase One Interview Participants - Mindfulness Facilitators

Number	Gender	Country of Residence	Occupation	Work Setting	Type of MBI Delivered	Format of MBI Delivered
F 1	M	Australia	Counsellor	Carers Association	MiCBT[1]	Group-based program with additional individual sessions
F 2	F	United Kingdom	Social worker	Cancer service	MBCT-Ca[2]	Group
F 3	F	Australia	Social worker	Palliative care service	MBSR[3]	Individual sessions
F 4	F	Australia	Psychologist	Mindfulness organisation	MBCT[4]	Group
F 5	F	Australia	Counsellor	Carers association	MiCBT[1]	Group-based program with additional individual sessions
F 6	M	Australia	General practitioner	Cancer care and academic teaching in health	Mindfulness for cancer, lifestyle and wellness	Group
F 7	F	United States of America	Palliative care medical specialist	Palliative care service	MBSR[3]	Individual sessions
F 8	F	Australia	Psychologist	Mindfulness organisation	MBSR[3]	Group
F 9	M	Australia	Counsellor	Cancer service and bereavement support organisation	MBSR[3]	Group or individual sessions depending on need
F 10	F	Australia	Counsellor	Bereavement support organisation	Mindfulness-based Somatic Therapy	Group or individual sessions depending on need
F 11	M	Malaysia	Palliative care medical specialist	Palliative care service	MBST[5]	Individual sessions
F 12	M	Australia	Psychologist	Palliative care service	ACT[6]	Individual sessions

[1]MiCBT = Mindfulness-integrated Cognitive Behaviour Therapy; [2]MBCT = Mindfulness-based Cognitive Therapy- Cancer; [3]MBSR = Mindfulness-based Stress Reduction

[4]MBCT = Mindfulness-based Cognitive Therapy; [5]MBST = Mindfulness-based Supportive therapy; [6]ACT = Acceptance and Commitment Therapy

As shown in Table 3, of the twelve mindfulness facilitator participants, seven were female. Nine participants lived and worked within states of Australia, including three in Tasmania, two in New South Wales, two in Victoria and one participant each in South Australia and Queensland. Of the three international participants, one resided and worked in Malaysia and one lived and worked in the United Kingdom. The third international participant was residing in the United States of America at the time of interview but described having offered mindfulness-based interventions both in America and South Africa in palliative care settings.

The participants worked in a diverse range of contexts including palliative care services (n=4), a carer support organisation (n=2), mindfulness centres (n=2) and a cancer-care setting (n=1). Two individuals were working across two organisations: one in a combination of cancer-care and teaching health providers in an academic setting and one in cancer care and bereavement. The occupational backgrounds of research participants included counselling (n=4), psychology (n=3), social work (n=2), palliative care medical specialists (n=2) and a general medical practitioner (n=1).

A range of mindfulness-based approaches were used by the research participants including (MBSR) a mindfulness-based stress reduction program (n=4), a mindfulness-integrated cognitive behavioural therapy (MiCBT) approach (n=2), a mindfulness-based cognitive therapy (MBCT) approach (n=1) and mindfulness-based cognitive therapy for cancer (MBCT-Ca) (n=1). Other participants used an acceptance commitment therapy (ACT) approach, a mindfulness-based supportive therapy (MBST), a mindfulness-based somatic therapy and a mindfulness for cancer, wellness and lifestyle approach. Four facilitators delivered mindfulness training exclusively as a group-based intervention, four in the context

of one-to-one, individual sessions, with two facilitators offering a group-based program, which included additional individual sessions of mindfulness training as part of the protocol. Two facilitators reported that they have provided mindfulness in both group and individual formats at different times, depending on client needs and preferences.

Phase Two- Participant Characteristics

The key characteristics of the informal palliative caregiver research participants interviewed in this study are provided in Table 4. Each participant has been assigned a pseudonym rather than a number. This is for two reasons: one, to protect their anonymity and two, to provide a more personalised, naturalistic representation of their experiences and descriptions in the presentation of findings. Caregiver characteristics, presented in the table, include gender, age, education, rural/ urban setting, occupation, type of MBI engaged, time of learning mindfulness in relation to caregiving, the type of palliative illness experienced by their significant other, whether caregivers received support from palliative care or other support services to aid with caring for their family member or friend, their relationship to the care recipient and time of interview relative to caregiving.

Table 4: Characteristics of Phase Two Interview Participants - Informal Palliative Caregivers

Caregiver Participant Pseudonym	Gender	Age	Education level	Occupation / Status	Location	Type and Format of MBI Engaged	Time of Learning Mindfulness Relative to Caregiving	Care Recipients' Illness / Receipt of SPCS	Caring for	Time of Interview Relative to Caregiving
Molly	Female	63	University	Teacher / Semi-retired	Rural	Head Space Mindfulness Smart Phone App – Self study	Whilst caregiving	COPD & heart failure / No SPCS	Husband	Currently caring
Jason	Male	32	University Doctorate	Clinical Psychologist / Working	Urban	ACT - Group	Before caregiving (8 years)	Catastrophic brain injury post heart attack / Yes SPCS	Best friend	6 months bereaved
Sarah	Female	42	University Masters	Doctor / Working	Rural	MBSR & ACT - Group	Before caregiving (long term practice)	Cancer / Yes SPCS	Mother	5 years bereaved
Laura	Female	41	Diploma	Business Manager / Working	Rural	MBSR with counsellor - Individual sessions	Whilst caregiving	Motor Neuron Disease / No SPCS	Husband	Currently caregiving
Gwen	Female	59	Diploma	Yoga teacher / Retired	Rural	MiCBT- Group and individual sessions	Whilst caregiving	Lymphoma / No SPCS	Sister	Currently caregiving
Ava	Female	60	University	Nurse / Working	Rural	MBSR – Group No SPCS	Whilst caregiving	Multiple Myeloma / No SPCS	Husband	Currently caregiving
Bill	Male	87	College	Manager / Retired	Urban	MiCBT- Individual sessions	Whilst caregiving	Cancer / Yes SPCS	Wife	Bereaved
Lorna	Female	82	University	Physiotherapist / Retired	Urban	MiCBT – Individual sessions	Whilst caregiving	Cancer / Yes SPCS	Husband	Bereaved

[1]ACT = Acceptance and Commitment Therapy; [2]MBSR = Mindfulness-based Stress Reduction [3]MiCBT = Mindfulness integrated Cognitive Behavioural Therapy; [4]SPCS = Specialist Palliative Care Service; [5]COPD= Chronic Obstructive Pulmonary Disease

As shown in Table 4, of the eight caregivers interviewed in this study, the majority were female (n=6). Ages ranged between 32-87 years old. A high level of educational attainment was noted across participants, consistent with the existing mindfulness literature. Five caregivers had university level education, one college, and two had diploma qualifications, with seven caregivers working in a professional stream and one in alternative health. All the caregivers in this study were residing in Tasmania. Using Australian Standard Geographic Classifications (ASGC - RA), all participants were living in a rural area (ABS 2018).

Mindfulness-based cognitive therapy (MBCT /MiCBT) and mindfulness-based stress reduction (MBSR) programs were the most common intervention type undertaken by caregivers, with three caregivers learning mindfulness in each of these formats. Two caregivers learnt mindfulness as part of an acceptance and commitment therapy program. For the majority of participants (n=7), mindfulness was learnt in a face-to-face format. One caregiver learnt mindfulness by way of a smart phone application. Four caregivers were caring for their spouses at the time of interview, with cancer the most prevalent terminal illness. Four caregivers were bereaved at the time of interview. With regards to the time of learning mindfulness relative to caregiving, the majority of caregiver participants (n=6) had learnt mindfulness whilst caregiving.

4.5 Methods of Data Generation

This section describes the methods of data generation used in this study. It explains and justifies the use of semi-structured and intensive, in-depth interviews as the methods of data generation. Whilst the term ‘data collection’ is commonly used in the reporting of qualitative research, the term ‘data generation’ is used in this thesis. The concept of data generation is consistent with a constructivist grounded theory methodology, which argues

that data is generated in the interactional process between participants and the researcher, as participants reflect on and give voice to their experiences (Brinkmannn & Kvale 2015). The key processes involved in conducting interviews across both phases are outlined. The next section details the methods of data analysis employed in this study, demonstrating a congruence with constructivist grounded theory, as the guiding methodological framework in this study. The detailed reporting of this study's data generation and analysis methods display a transparency of research practice and allows for the determination of rigour. Whilst presented here in this chapter as sequential sections for the purposes of clarity it should be noted that consistent with a grounded theory approach, data generation and analysis informed each other through a simultaneous and cyclic process.

4.5.1 Qualitative Interviews

In this qualitative study, across both phases, interviews were employed as the data generation method. This section will introduce and justify the choice of qualitative interviews, specifically the choice of semi-structured and intensive interviews. It will detail the key elements of the interview process and address their alignment with the ethical conduct of research in the setting of end-of-life caregiving.

Qualitative researchers have a range of choices when it comes to data generation methods. The critical considerations guiding the choice of method are the purpose of the research, the questions being asked, and congruence with the adopted methodological framework (Creswell 2013; Mason 2002). Prior to conducting this study, a review of the methodological literature was undertaken to consider the strengths and limitations of different qualitative research methods, including interviews, focus-groups and observational methods. Interviews were chosen as the most appropriate data generation method for this

study, consistent with the aims of exploring, in-depth, the experience of learning and using mindfulness whilst caregiving at the end of life. Interviews are a well-established qualitative research method in the fields of health and social sciences (Brinkmannn & Kvale 2015; Taylor 2005), valued for their ability to gain a rich 'emic' or insider view of a process, event or experience (Lincoln & Denzin 2005; Liamputtong & Ezzy 2005).

Within palliative care and bereavement settings specifically, qualitative interviews have proved to be an accepted research method for patients and caregivers (Donnelly, Michael & Donnelly 2006; Gysels, Shipman & Higginson 2008b) and have provided insight into what are often deeply personal experiences, which 'are not accessible through more structured questionnaire methods' (Taylor 2005, p 41). Interviews are also the most widely used data generation method in grounded theory studies as they enable in-depth exploration of a studied experience and the ability to ask further, probing questions for more nuanced understanding and theory development (Charmaz 2006). They are also favoured over methods such as focus groups when research is conducted with potentially vulnerable populations (Taylor 2005), with the view that the research encounter is 'less encumbered by social pressure and allows the interviewee to speak with greater candour about complex, sensitive and or yet to be explored topics' (Roller & Lavrakas 2015, p 95).

Qualitative interviews can take three different forms characterised by the degree of flexibility around structure of the research encounter: the structured, semi-structured and unstructured interview (Taylor 2005). This study employed the use of semi-structured interviews which allowed for a focused, yet flexible exploration of the way in which individual participants made sense of their experiences of mindfulness in end-of-life caregiving (Lincoln & Denzin 2005; Liamputtong & Ezzy 2005). Semi-structured interviews

contrast significantly with the structured, survey-type interview which follows a rigid process of asking each interviewee the same set of explicit, predetermined questions in a prescribed order (Roller & Lavrakas 2015). The semi-structured interview also contrasts with the unstructured, conversational-interview, at the other end of the continuum, in which participants explore the topic of interest entirely on their own terms without the interviewer prescribing the agenda. Consistent with the practice of semi-structured interviewing, the researcher in this study mapped out the broad domains of interests represented by several questions in an interview guide. This guide was used flexibly, whereby questions were not asked in a prescribed order and were modified across interviews to pursue interesting leads and probe for a more nuanced understanding (Taylor 2005) of caregiver and facilitator experiences.

The semi-structured interview method was considered congruent with the aims and methodological framework of this study. For example, the method of data generation required in-depth conversation about the experience and meaning of learning and using mindfulness during end-of-life caregiving, but with the ability for the researcher to ask probing questions to further test the emerging theory.

Whilst semi-structured interviews were used as the method of data generation in both mindfulness facilitators and informal palliative caregiver interviews, there were differences regarding the depth and focus of the interviews. Semi-structured interviews vary based on how 'in-depth' they are, reflective of the interview's duration and the degree to which emerging data is unpacked to gain rich, contextual understanding (Brinkmannn & Kvale 2015). Interviews with caregiver participants were characterised as being more in-

depth and intensive, both in terms of time and detail of conversation. Charmaz (2006, p 25-26) describes in-depth, intensive interviewing in constructivist grounded theory as:

> Inviting participants to describe and reflect upon his or her experiences in ways that seldom occur in everyday life…that goes beneath the surface of ordinary conversations and examines earlier events, views and feelings afresh.

Another feature of intensive interviewing according to Charmaz's approach is the focused lens brought to interview encounter by narrowing 'the range of interview topics to gather specific data for developing our theoretical frameworks, as we proceed with conducting the interviews' (2006, p 29). For example, in undertaking this present study, the researcher increasingly focused the conversation towards elaborating and testing the emerging theoretical constructs as the interviews progressed, including staying open to divergent cases. In addition to their strengths, all methods of data generation have limitations or elements that require careful attention to ensure quality and rigour. Qualitative interviews are no exception. Perhaps their greatest 'limitation' or constraint is that they are resource intensive, demanding significant amounts of time to recruit participants, conduct the interviews and to transcribe and analyse data which involves immersion in many hours of audio-recordings and pages of written transcript (Creswell 2013). Cognisant of these demands, this study allowed time and resources for quality, in-depth data generation and to ensure that the interviews were ethically sound, which involved gaining active consent and a commitment by the researcher to create as much respect and safety as possible. Brinkmannn and Kvale (2015, p 84) assert that:

> Ethical issues permeate interview research. The knowledge produced by such research depends on the social relationship of interviewer and interviewee, which

rests on the interviewer's ability to create a stage where the subject is free and safe to talk of private events, recorded for later public use.

Additionally, this study appreciated that the effectiveness of interviews to generate rich data depends heavily on the researcher's skills to establish rapport and trust with research participants and to skilfully elicit their descriptions and sense-making of the studied phenomenon (Taylor 2005).

This study was mindful of the heightened importance of researcher skill when interviewing more vulnerable populations to ensure participants felt safe and supported in the research encounter and not further burdened by their research participation (Gysels, Shipman & Higginson 2008b). As outlined in Part I, the researcher had extensive experience as a palliative care social worker and six years of experience undertaking qualitative interviews across a range of sensitive topics and populations including palliative care, advanced care planning, aged care resident experiences and disadvantaged populations. This assisted in the researcher being able to both elicit rich and nuanced accounts of what it is like for caregivers to learn and use mindfulness whilst end-of-life caregiving and to support participants should they become emotional when talking about experiences.

4.5.2 Interview Schedule and Pilot Interview

In both phases of this study, careful attention was paid to the construction on a semi-structured interview guide that would support the gathering of quality, nuanced data to address the research aims and questions as outlined below.

Phase One - Interview Schedule and Pilot Interview

In Phase One of this study, prior to interviews with mindfulness facilitator participants, a flexible, semi-structured qualitative interview guide was developed and piloted. (Appendix 13). The guide was designed to elicit facilitators' experience and perceptions of using mindfulness-based approaches in their work with informal palliative caregivers. It had three broad domains of interest including perceived benefits, risks or challenges and key considerations in offering MBIs in the setting of end-of-life caregiving. Questions relating to these domains were carefully phrased to be open and not leading, with additional questions inviting participants to share other reflections or issues they considered to be important.

Piloting interview schedules prior to interviewing participants is recommended in qualitative research (Creswell, 2013). The interview schedule was piloted with a supervision team member, who has extensive experience as a mindfulness group facilitator and practitioner. Feedback was received in relation to the interview process and the phrasing and effectiveness of questions to facilitate in-depth discussion of the studied experience, as well as researcher skill and sensitivity. This pilot interview was conducted whilst the supervision team member was overseas, enabling testing of Skype technology, planned for use in the interviews. The experience revealed that the technology worked well and was feasible to use.

Phase Two – Interview Schedule and Pilot Interview

In Phase Two of this study, a semi-structured interview schedule (Appendix 14) was constructed and piloted with the aim of eliciting caregivers' lived experience of learning and using mindfulness whilst end-of-life caregiving. In contrast to the facilitator interviews, there

was an intent to gather more detailed, in-depth interview data to understand how caregivers made sense of their experience and what mindfulness offered. The schedule incorporated more prompting questions to elicit specific examples to better understand the impact of learning and using mindfulness as an informal palliative caregiver. Effective prompting for more nuanced understanding and description is considered a critical interviewing skill (Patton 2015). The interview schedule also incorporated reference to emerging data categories, derived from Phase One data generation and analysis with mindfulness facilitators, to enable further testing and refining of the emerging theoretical concepts. More sensitive questions were placed toward the latter part of the interview guide to enable time to build trust and rapport in the research encounter. The interview guide was piloted with a peer who had the experience of both having engaged in a mindfulness-based intervention and who had cared for a palliative family member.

It is important to note that the interview guide was used flexibly during both phases of interviewing. Whilst having broad domains of interest, there was a commitment to be open to how the interview might unfold and to follow important threads of participant conversation, rather than follow a pre-set ordering of questions. Opportunities were also provided throughout the interview for participants to offer additional comments or observations.

4.5.3 Conducting the Interviews

This section describes key aspects of the interview process across both study phases and how they were informed by a constructivist grounded theory approach. Key aspects described include: (1) interview location and mode, (2) establishing rapport, sharing

information and power, (3) managing upset and interviewing for depth, and (4) data recording, transcription and management.

Location, Duration and Mode

The location, duration and mode of Interviews varied across both Phase One and Two. The first phase of the study (mindfulness facilitator interviews) engaged a broad range of research participants across diverse geographical locations within Tasmania, nationally and internationally. Due to the prohibitive costs of travel, the mediums of telephone (n=7) and Skype with video (n=3) were used to interview participants residing in locations other than Tasmania, with participants choosing their preferred medium. Of the three Tasmanian interviews, two were conducted in person, one at a participant's workplace and one at a community centre. The third participant preferred to be interviewed by phone. It is acknowledged that conducting interviews by phone, whilst enabling reach to a broader number of participants, also carries the limitation of not being able to observe non-verbal communication (Roller & Lavrakas 2015, p 59). Cognisant of this limitation, the researcher employed active listening skills. For example, attention was paid to paralinguistic communication such as tone, emphasis on certain words, pauses, sighs, laughter and silences. Encouraging responses such as 'yes', 'okay', 'I see', and use of prompting questions such as 'can you tell me more about that?' were used to convey active listening in the absence of being able to convey these cues visually. The use of Skype with video features enabled greater observation of nonverbal communication. However, due to issues with internet connectivity within Australia this was not readily possible for all participants.

Facilitators were offered as much choice in the interview process as possible, invited to nominate not only the mode, but the interview date and time of interview, according to

their needs. For the international research participants there were large time differences between our countries. To be responsive to their preferences and to allow for the time-zone difference, interviews were sometimes conducted late at night or early morning (my time) to enable participation. Mindfulness facilitator interviews lasted between 45-90 minutes, with a total of 12.61 hours of interview data recorded in this phase.

In Phase Two of this study, all caregiver interviews were conducted in-person within Tasmania. This was based on an ethical concern to be physically present with caregivers to build rapport and ensure an enhanced sense of support. To be respectful and responsive to participants, some of whom were still actively caring, the site of the interview was determined by caregivers. In consideration of managing issues of researcher safety, practices were instituted to advise when and where interviews were being conducted, with the researcher checking-in with the supervision team on leaving the interview location. Enabling caregiver choice in terms of where their interview would take place, demonstrated a commitment to offset the power asymmetry between the researcher and the participant previously discussed as one of the key ethical considerations in this study (Green & Thorogood 2014; Ehrlich & Walker 2018; Gysels, Shipman & Higginson 2008b). It was anticipated caregiver choice of interview location would also support a greater sense of comfort and safety regarding study participation. Two participants chose to undertake the interview in their workplace, two in a community library meeting room and four participants chose their own homes as the site for interview.

Interviewing caregiver participants in their own home, brought a different quality to the interview process, providing an enriched understanding of context. As Sivell et al. (2015, p 2) argues, 'the home can be very different to other settings, it's not just the location, but an integral part of the interview itself'. Being with caregivers in their own

environment surrounded by personal artefacts, photographs of loved ones and their everyday things; the books that they are reading, flyers of events they were going to attend and the pets at their feet, enabled a greater sense of who they were and what was important to them. Memos were written throughout the data generation phase of this study. Two examples are provided in Appendix 15 and Appendix 16. These memos reflect on how interviewing caregivers in their home contributed to an enriched understanding of participants' lived experience of caregiving and insight into how learning and using mindfulness might have looked and felt like in this context. In one particular case, interviewing Bill at his home was particularly profound, as he showed me the sun room in which he had cared for his wife and where she had also died.

The duration of informal palliative caregiver interviews ranged between 1.5 and 3 hours in duration, with a total of 19.5 hours of interview data gathered in this phase. Establishing context, in terms of who they were and the significant events in their lives appeared to be important for caregiver participants in the telling of their experiences of learning mindfulness and what it meant to them. Several caregivers spent a lot of time talking about their work life and what that meant to them, while others detailed the significant challenges they had faced in their lives. This meant foregrounding the participants' unique and individual way of telling their stories, taking time to listen to context and then weaving in relevant questions from the interview guide when appropriate, to further examine emerging theoretical categories.

Establishing Rapport and Sharing Information and Power

This study, in its approach to data generation and the building of rapport, sought to adopt Weber's position of 'Verstehen' wherever possible by providing a warm, humanistic

and empowering approach to interviewing, as opposed to positioning the researcher as an objective, distanced scientist. The researcher chose to disclose, to each interview participant, her previous experience of having worked as a palliative care social worker, her personal experience of caring for her father and her subsequent learning of mindfulness. Consistent with a constructivist grounded theory methodology, this approach demonstrated a preparedness of the researcher to be open and genuine in the research encounter (Charmaz 2006). This had the effect of establishing an early rapport with participants, through a sense of shared experience and vulnerability. This approach also reflects the 'strengths perspective' and its foundational values of respect, trust and empathy (Saleeby 2012). Effective rapport is regarded to offset some of previously mentioned power dynamics between 'a societally defined 'expert' (the researcher) and the research participant' (Ehrlich & Walker 2018 p 1012). Further, rapport is critical to participant willingness to talk openly and in depth about their experience, which has important implications for the quality of the data generated (Hitchings 2012; Sivell et al. 2015). Evidence of the researcher establishing rapport in this present study is provided by Ava, one of the caregiver research participants. Ava expressed surprise after the interview that she was able to talk in such an open and detailed way about her experiences in caregiving, and life more broadly, that were ordinarily very difficult for her to talk about:

> *You were very kind and really present during the interview and listening to what I was saying. You understand, and that made it easier for me to talk, where under normal circumstances I get quite anxious and stop talking (Ava).*

The upfront 'positioning' of the researcher in relation to the study topic may also have influenced the decision for four facilitators to disclose their own personal, as well as professional experience, in the context of mindfulness and end-of-life caregiving:

> *My experience, just to let you know where my experience is coming from, is that I've been close to a lot of people who have died and involved in their care and stuff like that - a lot of friends and family* (F 8).

> *My father died of leukaemia…I took mindfulness into that experience with my father. I had not had a good relationship with him. He was a harsh man. So, there was this whole journey with me learning to be present with him as a vulnerable man in a hospital bed about to die and being terrified* (F 4).

Other aspects of redressing power asymmetries and building safety and rapport included sharing information about the research process and addressing participant concerns at the start of each interview. Within social work, there is a euphemism that suggests 'knowledge is power', highlighting that to feel empowered, people need to have access to information relative to the situation they are navigating (Fook 2016). Cognisant of this, the researcher explained her approach to the research interviewee and what both mindfulness facilitator and informal palliative caregiver interview participants could expect. She explained her view of the interview process as a 'conversation with a purpose' (Burgess 1984, p 102) and that whilst she had a few questions that might help orientate the research, there was an intention to follow the threads of conversation as they occurred. Participants were reminded that they could choose to take a break, stop the interview or decline to answer questions they felt uncomfortable with, at any time. Only one caregiver asked to take a short break. Gwen asked for the audio recording to be paused momentarily so she could

qualify an event that had occurred regarding her sister for whom she was caring, 'off-the-record'. She expressed that she didn't want the event or her feelings to be part of her interview transcript. The tape was stopped, with it being turned on again when she was happy for the recording to continue. Empowering the mindfulness facilitator interview participants, in Phase One, to make choices around their safety and comfort was important too, as most interviews were conducted by phone thereby resulting in an absence of visual cues to indicate potential discomfort. In Phase Two, informing and empowering caregiver participants regarding the interview process and their choices in sharing what were often emotional experiences, was similarly important.

Interviewing for Depth

Both mindfulness facilitator and informal palliative caregiver interview participants, whilst keen to participate in the study, came with a shared concern that they would not be able to offer anything of benefit. Attention was paid to cultivating participant confidence in their ability to provide valuable insight into what it was like to learn and use mindfulness in end-of-life caregiving using their own words.

A challenge or early concern of the mindfulness facilitator interview participants in Phase One, who worked in sectors other than palliative care, was their ability to recall and reflect on the experiences of teaching mindfulness to informal palliative caregivers as opposed to other populations. To support participants to recall and offer more specific descriptions of the perceived effect of caregivers learning mindfulness, probing questions were asked to focus their reflection on specific caregivers with whom they had worked. This had the effect of inviting the research participant to anchor their reflections in particular cases and resulted in more nuanced data.

For the caregiver interview participants, there was a common challenge for participants to find and say '*the right words'* to describe their experience of mindfulness, with many caregivers like Laura stating*, 'It is more for a felt experience'*, or '*I tell you, it's not easy to describe in words what mindfulness is and what it offers you'* (Bill). The researcher moved to normalise this concern, sharing that most of the people interviewed encountered a similar challenge, as evidenced by the following data extract from an interview with Gwen:

> *Everybody I've talked with so far has found the same thing - it is so hard to get the words around this. So, you're not alone in that. People will look at me exactly as you have done and go, "Oh I don't know how. I don't know what the word is. I don't know how to describe what it does". Take your time* (LJ).

With encouragement from the researcher to play around with words or images to better describe their experiences, informal palliative caregivers were able to offer powerful accounts and insights into what it was like and what it meant for them to learn and use a mindfulness-based approach whilst caregiving.

Managing Upset

Managing upset was a feature of both mindfulness facilitator and caregiver interview phases, although these elements were more prominent in the informal palliative caregiver interviews as described below.

Whilst facilitators reflected primarily on how they have observed caregivers to engage with and derive benefit from learning mindfulness during end-of-life caregiving, three facilitators chose to talk about their own personal experiences of caring for a significant other with a palliative illness and one disclosed a personal bereavement experience during the interview. In Phase Two, all caregiver participants shared their

experiences of end-of-life caregiving, with four of them also talking about the death of their significant other and the bereavement that followed. As has been reported in earlier studies, many of the caregivers cried as they shared these experiences during the interview. The researcher, comfortable with and experienced in supporting people in distress, acknowledged the participants upset, listening empathetically as they shared their story. Participants were asked if they needed to stop or take a break from the interview. No participant chose to stop the interview due to being upset, indicating they wanted to keep talking, with many saying that it was cathartic to share their experience. The emotionally sensitive nature of the conversations and the depth of personal disclosure in the caregiver interviews underscored the importance of the researcher skilfully and empathetically managing the conclusion of the interview or 'leave taking' (Drisko 2016), with as much care as that taken as the beginning of the research encounter. A strengths-based approach was employed to support participants to come back to a place where they felt emotionally centred and resourced to transition out of the interview space. At the end of each interview the researcher reflected-back to participants some of their unique strengths identified during the research conversation and thanked them for their courage to openly share some of their most challenging experiences.

Following the interview, participants were also provided with a contact list of available support services that could provide additional support (Appendix 17) as well as being offered the opportunity for a post- interview debriefing by another member of the research team, three of whom have clinical psychology backgrounds. No follow-up was requested.

4.5.4 Data Recording, Transcription and Management

In both phases of the study, interviews were audio-recorded following consent from participants. This enabled the detailed and accurate capture of participants' words, which is strongly advocated in the qualitative literature (Creswell 2013). This practice supports a trustworthy and nuanced analysis of participant perspectives and provides the option of 'member checking' or participant review of their interview if requested (Liamputtong 2013). Whilst participants gave permission for note-taking during the interview, this seldom occurred with the view that it took attention away from listening deeply to the interview participant.

Detailed field notes were recorded in a research journal immediately following the interview to capture reflections on the interview process, the impact of the research setting, participants' nonverbal communication, emotional responses, as well as the exchanges that occurred after the tape-recorder was turned off. Following the interviews, the audio recordings were transcribed verbatim: three by the researcher and seventeen by a professional transcription service. Rationale for sourcing professional transcription hinged on methodological considerations and the logistics of time. The preferred option was for the researcher to transcribe all interviews. This would enable the greatest familiarisation with the data and a full-immersion in the emergent narratives (Liamputtong 2013). However, grounded theory methods require analysis to occur alongside of data collection (Charmaz 2006; Strauss & Corbin 1998). The length of time required of the researcher to transcribe each interview (Brinkmannn & Kvale 2015) would have prohibited timely analysis and the collection of data within an already limited PhD timeline. Transcripts, however, were read whilst listening to the taped interview to aid familiarisation with the nuanced recordings,

and to enable amendments of the transcripts for accuracy, where necessary. Interview participants were informed both in the information sheet and verbally at the start of the interview, of the option of receiving and reviewing the typed transcription of their interview to check for accuracy themselves. No participants requested a copy of their transcript.

In Phase One of the study, mindfulness facilitators and researchers were assigned a number to protect the anonymity of their data. In Phase Two, the caregivers were assigned pseudonyms. This strategy provided a way to identify participants as either caregivers or mindfulness facilitators in the analysis of the data. Only the research team had access to the master-list linking participants to the de-identified data, which was stored separately. Table 5 below provides an overview of the conventions used in this study when presenting data.

Table 5: Outline of Conventions Used in Presenting Data Extracts from Interview Transcripts

Conventions Used in Presenting Data Extracts from Interview Transcripts
… indicates deleted text LJ: refers to the researcher [ ] indicates text inserted for context - indicates a pause or stop in narrative or conversation F 1 indicates a mindfulness facilitator interview participant __ sigh, laugh, etc) indicates body language, paralinguistic cues Each caregiver interview participant has been assigned a pseudonym name and this name is used when citing data offered by them. A unique number, as opposed to a pseudonym, has been ascribed to each mindfulness facilitator to differentiate the two samples. To identify data extracts from mindfulness facilitator interviews the following convention is used (F 12) The word 'participants' is used to indicate when an idea or experience was expressed by both facilitators and caregivers. 'Facilitators' is used to refer to mindfulness facilitator research participants and 'caregivers' refer to the caregiver research participants. (n=) refers to the total number of participants expressing the same idea or experience. Participant quotes are italicised and marked with single quotation marks to make it immediately clear where supporting data has been taken from interview transcripts.

4.6 Data Analysis

Data analysis within grounded theory occurs concurrently with data collection (Glaser & Strauss, 1967). This fluid and iterative process of analysis does not easily lend itself to linear description. However, this section will distil how analysis was undertaken in this study, drawing on Charmaz's (2006) constructivist grounded theory approach. First, it addresses the reconciliation of researcher exposure to the extant literature and the importance of reflexivity. The different coding cycles, theoretical sampling, analytic memo-writing and diagramming used in this study to construct an interpretive understanding of

the experience of learning and using mindfulness-based approaches in end-of-life caregiving are then presented. Additionally, examples depicting different aspects of the analysis process are provided throughout this section to support clear understanding and determination of methodological rigour.

4.6.1 Exposure to Extant Literature and Researcher Reflexivity

Data analysis proceeded with a strong commitment to remain open to and 'grounded in' the emerging data. Whilst many proponents of grounded theory encourage a delay in intensive engagement with the literature (Glaser & Strauss 1967), other grounded theorists (Charmaz 2006; Clarke 2005; Strauss & Corbin 1990) accept that researchers will have been sensitised, to varying degrees, by their past research and engagement with the literature (Charamaz 2008a). In the case of doctoral studies, an early review of existing studies is often mandated to establish the scope of the PhD research. This study, for example, began with a review of the literature to identify what was known, as well as what was not known, about mindfulness-based intervention for informal palliative caregivers. However, after identifying a lack of in-depth qualitative studies, a decision was made to delay intensive review of the broader qualitative MBI and informal palliative caregiver literatures until after data analysis and the construction of the grounded theory, to limit preconceived theoretical concepts being imported into this study. Attention was placed on maintaining a strong commitment to researcher reflexivity, described by Charmaz as the imperative of 'recognizing prior knowledge and theoretical preconceptions and subjecting them to rigorous scrutiny' (2008a, p 402). Researcher reflexivity was operationalised in this study by engaging in regular supervision sessions, the use of a research journal and

analytical memo-writing. It was also supported by the systematic, yet flexible guidelines of analysis discussed below.

4.6.2 Overview of the Data Analysis Process Used in this Study

Consistent with Charmaz's (2006) constructivist grounded theory data analysis, this study cycled through several different phases including:

1) the collection, immersion in and initial coding of data;
2) initial memo-writing and raising codes to tentative categories;
3) focused coding, advanced memo-writing and refining categories;
4) attention to divergent cases
5) theoretical sampling, seeking specific new data;
6) theoretical memo-writing, distillation and adoption of key categories as theoretical concepts;
7) sorting memos and diagramming the relationship between key conceptual categories / or theoretical concepts;
8) providing an explanatory model or theoretical account of learning and using a MBI during end-of-life caregiving.

Figure 3 provides a visual depiction of the different phases and activities of analysis undertaken in this study.

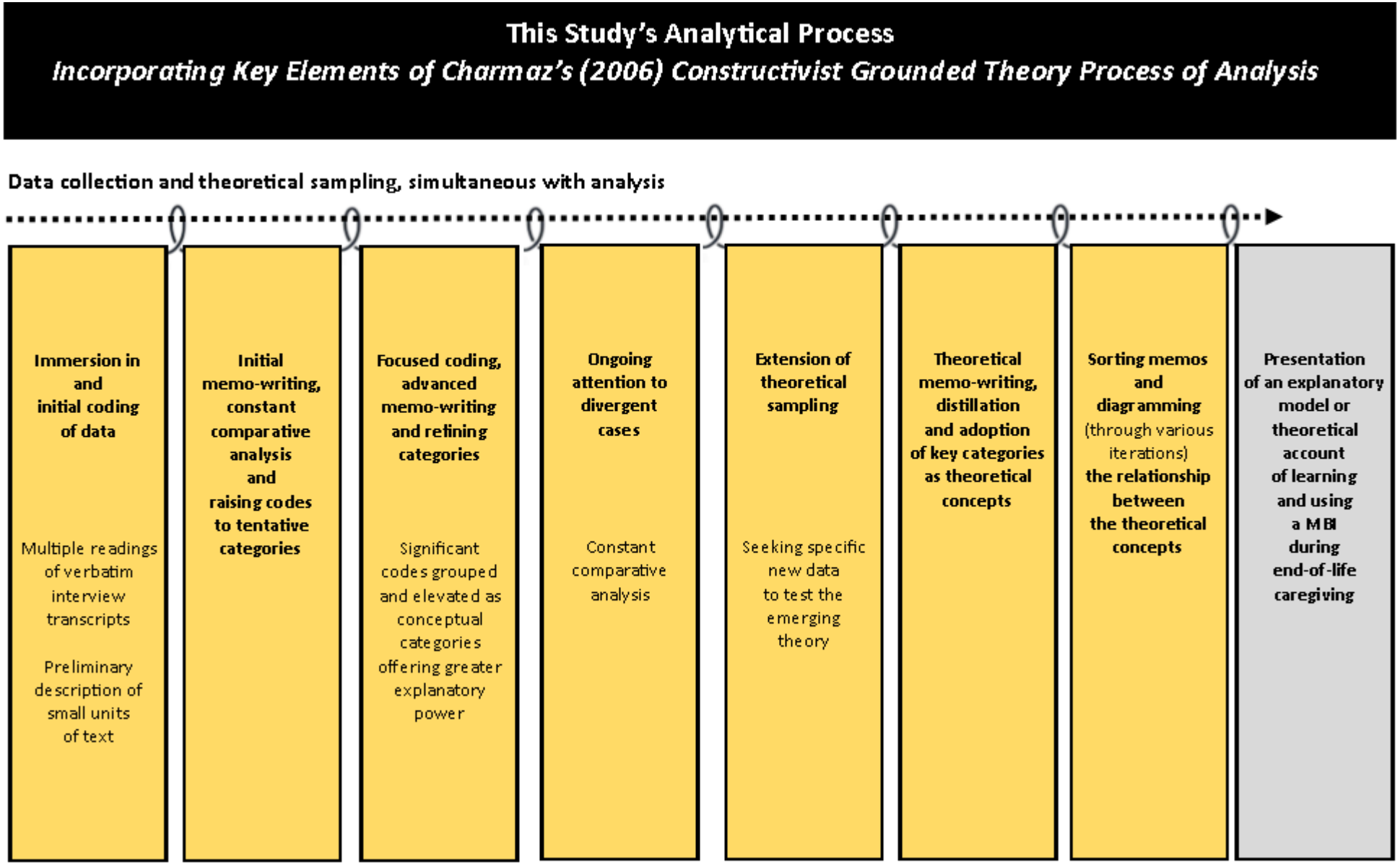


Figure 3: Depiction of the Constructivist Grounded Theory Analysis Process Used in this Study

The following section provides a narrative description of the key aspects of this analysis process and what it looked like in practice, evidencing examples of coding, categorisation and theory development specific to this study.

1) The Collection, Immersion in and Initial Coding of Data

Coding and analysis of interview data occurred as it was collected. Following transcription of each interview, the written transcript, along with research notes pertaining to each interview were read multiple times. At least one of these readings was undertaken whilst listening to the audio recording of the interview. Consistent with rigorous qualitative research practice (Creswell 2013), this approach aided familiarisation with the data, the individual participants and their life contexts, as well as the emotional tone of each interview.

Analysis was supported using different grounded theory coding cycles. The first coding approach employed in this study was 'open' or 'initial coding' (Strauss & Corbin, 1998). Initial coding involved assigning each line of data a preliminary descriptive code to avoid prematurely discounting important concepts. See Appendix 18 for an example of initial, line-by-line coding of a caregiver interview extract. Where possible these codes incorporated the words offered by participants themselves referred to as 'in vivo codes' (Charmaz 2006; Glaser & Strauss 1967) in order to 'stay close to the data' (Charmaz 2011, p 361). Initial codes were also written in the form of 'gerunds' or action words to preserve a grounded theory focus on action or processes. For example, an early in vivo code from a facilitator transcript was 'untangling from thoughts'. This code described how, through learning mindfulness, caregivers gained the capacity to be less caught up in and overwhelmed by their thoughts. This active in vivo code preserved the sense of caregivers

working to gain some distance from their thoughts, within which they ordinarily experience feeling entrapped or entangled. Another example of initial coding, '*Trying to determine what is our life now',* was derived from the analysis of an early caregiver interview (Molly). This in vivo code was used to encapsulate caregivers' sense of disorientation and struggle as they tried to come to terms with their significant other's terminal diagnosis and the subsequent disruption brought to their lives. Utilising the method of constant comparison, a hallmark of the constructivist grounded theory approach (Glaser & Strauss 1967), these inductively derived codes were compared with data both within and across other interviews to identify similar, as well as new and divergent codes.

Early in analysis, it became evident that the data was incredibly complex and interwoven. Three overarching processes were identified within the data and used to support the early sorting or organisation of the complex threads emerging from analysis. These were (1) describing the value and benefit of mindfulness, (2) considering the risks or adverse effects of learning mindfulness in end-of-life caregiving and (3) identifying key considerations of program development and implementation. These early overarching processes were not surprising as they reflected the key research questions. As analysis progressed, however, these tentative overarching processes shifted significantly in response to the identification of new and divergent codes unearthed by the ongoing use of the constant comparative method. For example, the overarching process of risk was folded into a larger theme of key considerations as this did not prove to be a large or stand-alone entity. New and unexpected categories emerged as the data analysis progressed, such as the 'illness context', 'the caregiving landscape' and 'the self-care disconnect', leading to the evolution and re-conceptualisation of the three tentative overarching processes (Figure 4).

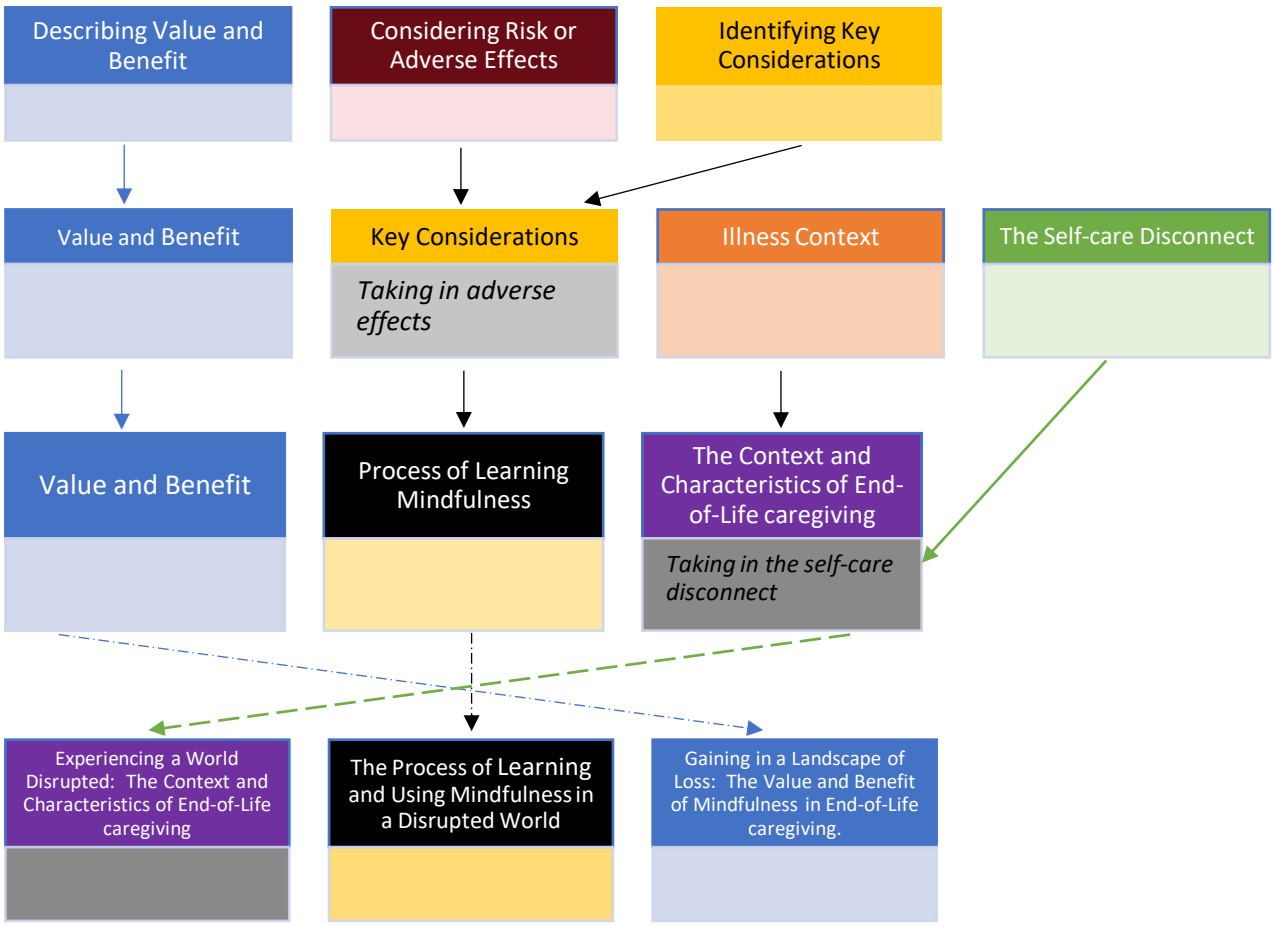


Figure 4: Evolution of Overarching Processes Through Analysis

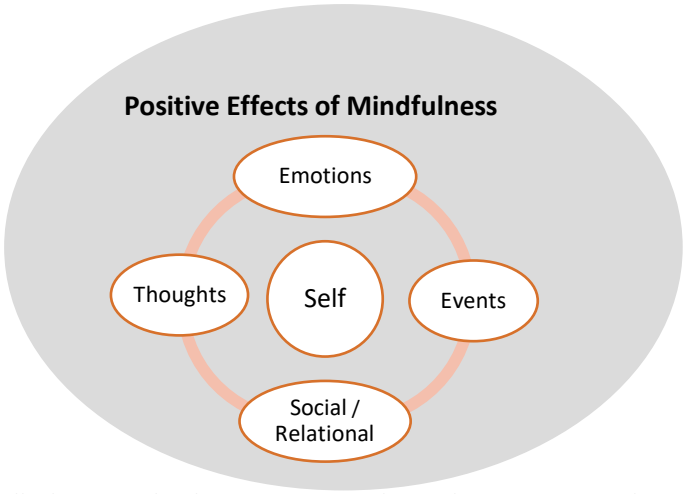
2) Initial Memo-Writing and Raising Codes to Tentative Categories

Analytic memo-writing, a core element of grounded theory analysis (Strauss & Corbin 1998) was undertaken throughout this study. Described as 'sites of conversation with ourselves about our data' (Clarke 2005, p. 202) memo-writing is a process whereby the researcher documents his/her emerging understanding of the data as it is collected and analysed, including the evolution of codes and conceptual categories. Towards the later phase of the analytic process, memo-writing supported the process of distilling the properties of the categories and relationships to each other. Memo-writing functioned as a critical catalyst in developing a deeper understanding of the data and the construction and

testing of theoretical concepts in this study. It was also used to reflect on the research process, more broadly.

Initial memo-writing in this study provided a way of reflecting on the preliminary coding and the identification of common threads that could pull similar codes together to form larger more meaningful units of analysis. For example, in examining and writing about the range of initial codes, it became evident that there was a strong sense of movement or positive shift in the way in which caregivers were seen to relate to their thoughts, feelings and events happening around them, as a benefit of learning mindfulness. In response, the category of 'relating differently to thoughts, feelings and events' was considered a potentially useful filter for the coding and analysis of subsequent data. However, consistent with a constructivist grounded theory approach, it was considered tentative to remain open to the emerging data (Charmaz 2006). Figure 5 provides an example of such memo-writing.

Memo: Raising Tentative Categories from Reflecting on Initial Codes



Initially, because the data was so complex and interwoven, coding the positive effects of mindfulness as they related to (a) emotions, (b) thoughts, (c) social and relational, and (d) self, provided a way to break down and make sense of the effect of mindfulness for caregivers. However, I am beginning to see that across all these initial codes there are two key threads. The first common thread is a reported experience of caregivers coming to relate differently to thoughts, feelings, and events – underscored by a gaining of increased empowerment and ability to tolerate, or 'be with', as opposed to avoiding difficult experiences.

For now, a more apt description may be:

'relating differently to thoughts, feeling and events'.

The second thing that is increasingly evident in the data is mindfulness enabling a greater sense of connection with and care of themselves and others. For now, I will term these categories as 'enhanced care and connection with self' and 'enhanced care and connection with others'.

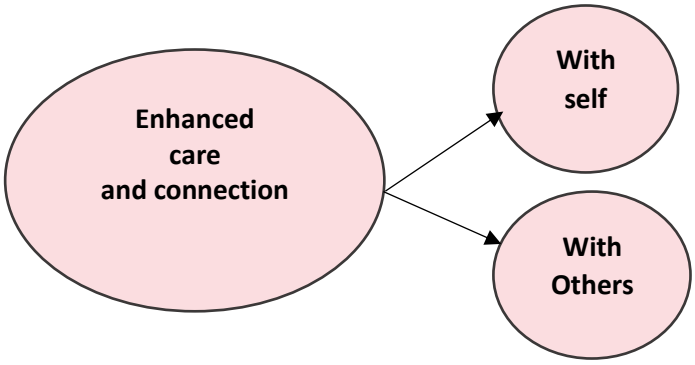


Figure 5: Raising Codes to Tentative Categories

3) Data Collection and Focused Coding

As data collection proceeded in this study a second cycle of grounded theory coding, 'focused coding' was used (Charmaz 2006). This coding strategy enabled the identification and organisation of the most significant and frequently occurring codes across interviews. Supported by initial memo-writing and perceiving emerging patterns in the data, related groups of codes were taken into larger categories that could offer greater explanatory power. For example, the tentative category 'relating differently to thoughts, feelings and events' as a key benefit of mindfulness, identified through initial memo-writing and reflection of initial codes, was further developed through focused coding to reflect the emergence of two distinct processes. The new coding of 'stepping back from enmeshment' and 'stepping into a more grounded, present moment space' enabled a more nuanced and refined description of this category of benefit. Appendix 19 provides an example of progressing data analysis through this cycle of focused coding. In another example, the process of focused coding brought together a range of similar initial codes describing the skills, attributes and actions of mindfulness facilitators to form the larger category of 'facilitator variables' which had greater explanatory power to capture the essence of the data (Figure 6). This figure also demonstrates how data analysis progressed in the next cycle of coding, whereby the key category of 'facilitator variables' was raised to the concept of 'skilled and supportive facilitation'. This process enabled the category to be detailed and refined into a more analytical construct.

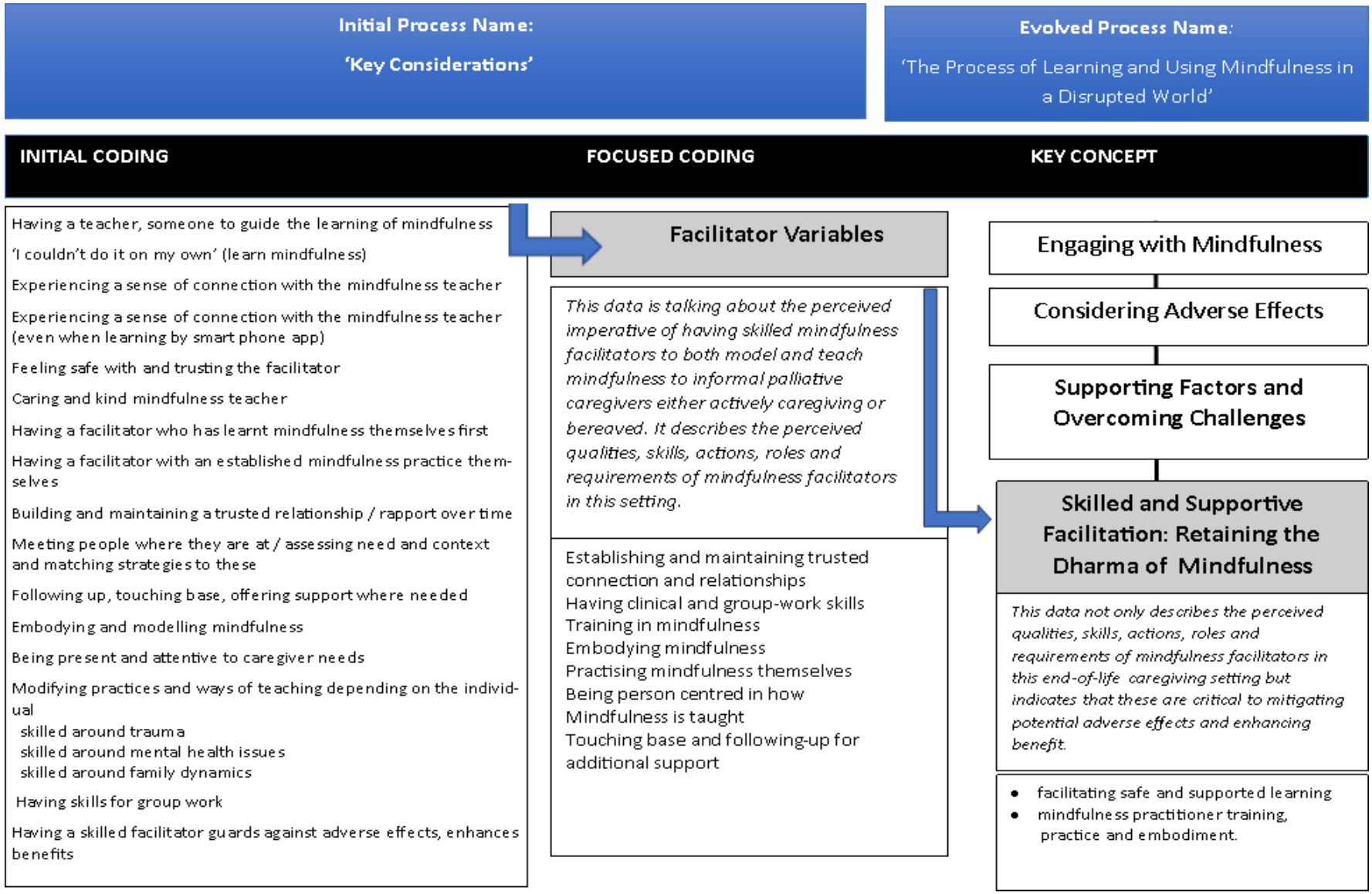


Figure 6: Progressing Through Initial and Focused Coding to Key Concepts

4) Attention to Divergent or Negative Cases

Throughout analysis and the ongoing process of constant comparison of new and existing data, specific attention was paid to data that diverged or contradicted other categories. This resolve to be open to and further examine cases that may contradict emerging theoretical understanding is strongly advocated in a grounded theory approach (Charmaz 2006 p 102). For example, after establishing a strong and reoccurring code of 'caregiver reluctance to consider and take care of own needs', Molly, who was caring for her husband with end-stage heart disease and chronic obstructive pulmonary disease, spoke of valuing and taking care of her own needs in caregiving. This contradiction was explored both at the time of interview with Molly, during analytic memo-writing and in subsequent interviews, as to why Molly's experience was so different. Preliminary memo-writing determined that Molly's experience was so different because she had received encouraging, positive messages about the importance of women taking care of themselves and their own needs through a lifetime of being a feminist. In subsequent interviews, questions were asked about the messaging that other caregivers had received, not only in caregiving, but in their lives more generally. No other caregivers interviewed spoke of receiving positive messages about the importance or value of self-care in their lifetime. Unlike Molly, these caregivers had assumed the narrative that self-care was selfish which underscored their resistance to thinking about their own needs prior to learning mindfulness. Consistent with a grounded theory approach (Bluff 2005), rather than dismissing this divergence, the ambiguity of Molly's case prompted more specific questioning in subsequent interviews to explore caregiver messages about self-care. This led to developing the earlier code of 'caregiver reluctance to consider and take care of their own needs' to a more refined theoretical concept 'the self-care disconnect'.

5) Theoretical Sampling

Consistent with a constructivist grounded theory methodology, further research participants were selected on their ability to test and develop emerging theoretical constructs (Charmaz 2006; Strauss & Corbin 1998).

Theoretical sampling was operationalised in three key ways. Firstly, this study decided to recruit and interview caregivers in the second phase of this study when it became evident that the emerging data generated from facilitator interviews required further testing and elaboration by individuals with direct experience of mindfulness in end-of-life caregiving. Secondly, theoretical sampling was operationalised by subjecting previous data to re-analysis in light of emerging theoretical concepts. Thirdly, additional questions regarding these new constructs were incorporated into subsequent interviews and helped narrow the focus to the emerging theory to enable the saturation of the key concepts and their properties. Consistent with grounded theory practices for theoretical sampling (Holtslander, Bally & Steeves 2011; Liamputtong 2013), these strategies facilitated greater understanding, testing and refining of the developing theory. For example, the emerging conceptual category of 'the self-care disconnect' was woven into subsequent caregiver interviews by asking new questions about how they engaged with the idea and practice of taking care of themselves and their own needs whilst caregiving. More specifically, the insights gained from Molly's interview about the importance of wider cultural narratives and messaging around self-care, led to the construction and asking of more pointed questions about the type of self-care messages caregivers had received in their life. The small number of informal caregivers in Tasmania with experience of MBIs and recruitment constraints prohibited more extensive theoretical sampling. However, sampling continued until the key

concepts of the theory were significantly saturated, or as described by Green and Thorogood (2014, p 122), the point of achieving:

> A conceptually dense theoretical account of the field of interest in which all categories are fully accounted for, the variations within them explained and all relationships between the categories established.

Saturation of the core conceptual categories was achieved at 20 interviews.

6) Theoretical Memo-Writing and Adopting Key Categories as Theoretical Concepts

Theoretical memo-writing, in addition to the initial memo-writing, constituted a further phase of analysis in this study. Theoretical memo-writing is described in grounded theory as an advanced process of refining the properties and relationships among different categories and thereby moves analysis to a more conceptual level (Charmaz 2006). In this process the most salient, explanatory categories were identified and adopted as key concepts. These concepts would become the core elements of the developing grounded theory accounting for the experience of learning and using mindfulness in end-of-life caregiving. This approach is congruent with Charmaz's constructivist grounded theory approach: 'we chose to raise certain categories to concepts because of their theoretical reach, incisiveness, generic power and relation to other categories' (Charmaz 2006, p 139). An example of theoretical memo-writing in the service of further refining and adopting key categories as theoretical concepts is provided in Appendix 20. The evolution of the theoretical concept of 'repositioning self' from early codes and categories is detailed below in Table 6, offering a visual depiction of this process of increasing conceptual refinement.

Table 6: Evolution of Theoretical Concepts

Ongoing Data Collection, Analysis and Memo-writing →			
Initial codes	**Tentative category**	**Focused codes**	**Theoretical Concept**
'untangling from thoughts' 'not being so caught up in emotions' 'not being pulled into the future'	'relating differently to thoughts, feelings and events'	'stepping back from enmeshment' 'stepping into a more grounded, present moment space'.	'repositioning self'

7) Sorting Memos and Diagramming Relationships Between the Key Conceptual Categories

Having written extensive analytic memos through the various cycles of data collection and analysis it became necessary to organise and weave them together into an analytic story: as an interpretive or theoretical account of the experience of learning and using mindfulness in end-of-life caregiving. Description of the parameters of each concept were specified, as were their relationship to other concepts, the conditions under which they arise and their consequences. This was achieved in this study by sorting memos by the tile of each key concept, undertaken initially in the computer program 'Microsoft Excel'. For each key concept, a detailed description of its properties and connections to other concepts, was entered into a spreadsheet along with multiple data extracts as evidence for the emerging interpretation. However, pursuing a more hands-on and visual approach by use of large sticky notes, was found to offer greater flexibility and testing of different arrangements of the key theoretical concepts and their associated memos. These large, coloured, sticky-notes representing the different concepts were compared, moved around and reordered in different ways to best explain and demonstrate their relationship to each other. Each of these different iterations were diagrammed. 'Diagramming', according to Da

Silva Barreto (2018, p 20), whilst not mandatory in grounded theory research, help to 'throw additional light on the textual context and they facilitate the mapping of the emerged categories and subcategories of the GT research'. The evolving diagrams undertaken in this study were refined through a process of returning to the analytic memos to ensure the key properties and noted connections between the key concepts were preserved in the visual depiction of the emerging theory.

4.6.3 The Analytical Outcome

Whilst developing theory is the primary aim, not all grounded theory studies achieve this, with many remaining at the level of description. In contrast, this study has developed a substantive theory or a theoretical account of the experience of learning and using a mindfulness-based approach in end-of-life caregiving, anchored in a specific context. It has done so through employing the systematic, yet flexible grounded theory guidelines of data collection, analysis and retaining a concerted focus on action, process, context and meaning. Writing and refining drafts of the theory through multiple iterations further honed the developed theory. In keeping with Charmaz's constructivist grounded theory view, this study does not perceive this developed theory as a fixed and absolute truth, but rather as:

> An interpretive portrayal of the studied phenomenon, that is provisional and contextual. Data do not provide a window on reality. Rather the 'discovered' reality arises from the interactive process and it's temporal, cultural and studied contexts (Charmaz 2000, p 524).

Whilst diverse ways of presenting the constructed theory are accepted in grounded theory studies, common to most is the presentation of 'a set of well-developed categories (e.g themes, concepts) that are systematically interrelated through statements of

relationship' (Strauss & Corbin 1998, p 22). The theory is often presented in diagrammatic form to illustrate the key theoretical categories or concepts, their properties and interrelationships (Liamputtong 2013). However, constructivist grounded theorists frequently embed their interpretive understanding within the narrative.

In this study, the theoretical outcome or interpretive understanding of what it is like to learn and use mindfulness in end-of-life caregiving is presented in a narrative form. The narrative seeks to preserve participants' voice and sense making, so as not to contribute to the invisibility of caregivers in palliative research (Aoun et al. 2017). However, the analytic rendering of the data has attempted as Charmaz (2006, p 151) describes, 'to focus and sharpen our view of these experiences' and enable 'these ordinary experiences to shine with bright meanings.' Ten conceptual categories under three overarching processes were generated through analysis (Table 7).

Table 7: The Ten Conceptual Categories of the Grounded Theory

Experiencing a World Disrupted: The Context & Characteristics of End-of-life caregiving	**The Process of Learning and Using Mindfulness in a Disrupted World**	**Gaining in a Landscape of Loss: The Value and Benefit of Mindfulness in End-of-life caregiving.**
The disorientating loss-filled landscape of caregiving	Engaging with mindfulness	Repositioning self
The self-care disconnect	Supporting factors and overcoming challenges	Engaging with the full range of experience
	Considering adverse effects	Connecting with and caring for self
		Strengthening relationships
		Realising a resourceful and empowered self

The next three chapters (Five, Six and Seven) sequentially discuss these findings as they relate to the three overarching processes. A conceptual diagram supplements this narrative, explicating the core categories, their properties and interrelationships. This constructed theory is presented in visual form and further explored in Chapter Eight, 'The Discussion'.

4.6.4 Achieving Rigour and Issues of Trustworthiness

Attention to and demonstration of research rigour has been an important concern in this study. Whilst research rigour in qualitative research (trustworthiness) is expressed in different terms to those used by quantitative research (reliability and validity) the central commitment is the same (Liamputtong 2013). This commitment is to undertake and report research activities in a rigorous, transparent and accountable way that is congruent with the guiding philosophical and methodological frameworks of the study (Creswell 2013). Whilst there is a long-established debate regarding the most appropriate measure of rigour (Carter & Little 2007), study rigour or quality in qualitative research is largely assessed by making a determination of 'trustworthiness' (Liamputtong 2013) or 'closeness to the truth' (Greenhalgh 2010). Lincoln and Guba (1985) developed four categories against which 'trustworthiness' can be assessed. These include credibility, transferability, dependability and confirmability.

Credibility relates to judging the 'believability' of study findings (Bryman 2012) or the level of congruence between the researcher's presentation of study findings and participant data. In this study, audio recording and verbatim transcription of interviews were undertaken to capture and preserve the accuracy of participants' words. Verbatim participant quotes are used extensively in the presentation of the research findings, with a deep concern to stay grounded in the data and honour the voices of participants. This

demonstrates a high level of connectivity and credibility between the original data and the researcher's theoretical rendering of this data.

Transferability as a criteria of qualitative research rigour or trustworthiness determines the application or transferability of findings to other contexts (Lincoln and Guba 1985): 'the degree to which qualitative findings inform and facilitate insights within contexts other than that in which the research was conducted' (Carptenter & Suto 2008, p 149-150). Findings in this study could be assessed as having potential for transferability. This study elicited the experience and views of people around the world who have been involved in the teaching and / or learning of mindfulness in end-of-life caregiving. However, the constructivist grounded theory methodology employed in this study, valued contextualised understanding (Charmaz 2006) and pursued the development of a substantive theory, as opposed to a formal theory applicable across contexts. Whilst the insights generated in this study of what it is like and what it means to learn mindfulness in end-of-life caregiving may be transferrable across other contexts, it was not the primary aim of this study.

The criteria of *dependability* denote the degree in which the research process and its myriad of activities is clearly articulated, logical and congruent with the guiding paradigms and methodologies employed (Liamputtong 2013). This study has demonstrated dependability through detailed recounting and description of the key research activities and by the provision of protocols and examples of data analysis extracts in the appendices.

Confirmability is the final criteria to assist in a determination of study rigour in qualitative research. Confirmability refers to 'whether a researcher has allowed his or her values to intrude to a high degree' (Bryman 2012, p 49). The premise of grounded theory, to remain open to and ground analysis in the studied data, has been an enduring commitment

in this study. As previously discussed, this entailed the researcher identifying her previous experiences and assumptions and positioning herself in relation to the research. The potential for these variables to influence the research process was monitored through the ongoing use of a self-reflexive research journal, analytical memo-writing and regular supervision sessions. This ongoing reflexive stance is regarded to increase study rigour and the trustworthiness of findings (Williams 2016) and is consistent with the qualitative research paradigm (Creswell 2013), which advocates 'rather than trying to eliminate these biases or "subjectivities" it is important to identify them and monitor them as to how they may be shaping the collection and interpretation of data' (Merriam 2009, p 15)

Confirmability can also be aided by triangulation or using more than one data source, through cross verification of the studied phenomenon (Liamputtong 2013). This study by interviewing mindfulness facilitators and informal palliative caregivers was able to offer a level of data triangulation. Whilst member checking is regarded as an additional avenue to enhance confirmability, no study participant responded to the offer to review their transcripts. The option of having others analyse the data at the same time, independently, is also regarded as a way of enhancing confirmability. However, within a constructivist grounded theory approach and qualitative research more broadly, seeking inter-rater reliability is not generally pursued. As Greenhalgh (2010) explains, this is because one researcher will inevitably be more involved in the data and have a more nuanced sense of things, whereas people coming into check codes and analysis may be more likely to rely on their own assumptions and biases. Rather than independently coding and analysing the data, three supervision team members reviewed two interviews each to appraise the author's analytical process of coding, categorisation and memo-writing, to assess the trustworthiness and confirmability of the emerging analysis with the original data.

Constructivist grounded theory, as the approach used in this study to understand the experience of learning and using a mindfulness-based approach in end-of-life caregiving, also has its own criteria for assessing study rigour. These include: credibility, originality, resonance and usefulness (Charmaz 2006) and will be addressed in the conclusion to the thesis.

4.7 Chapter Conclusion

The purpose of this research was to explore and develop a conceptual understanding of the experience of learning and using a mindfulness-based approach in end-of-life caregiving. Consistent with these aims and the philosophical standpoints of the researcher, a qualitative approach and constructivist grounded theory methodology was employed. This chapter has discussed the ethical considerations for conducting research in end-of-life caregiving. The research setting, sampling and recruitment processes have been described, and the research participants introduced. The methods of data generation, semi-structured and intensive, in-depth interviews and analysis processes were detailed, attending to the issues of rigour and congruence with a grounded theory methodology that provided the guiding framework to this study.

This thesis now progresses to Part IV which contains three findings chapters. These chapters will present the study findings and the theoretical understanding of what it is like and what it means to learn and use mindfulness during end-of-life caregiving.

PART IV: STUDY FINDINGS

This is the fourth part, of this five-part thesis. Part IV presents the study findings. It consists of three chapters. Chapter Five 'Experiencing a World Disrupted: The Context and Characteristics of End-of-life caregiving' provides a rich and detailed account of what it is like to care for a terminally ill family member or friend. Chapter Six 'The Process of Learning and Using Mindfulness in a Disrupted World' lays bare caregivers experience of learning mindfulness in such a setting, including how they came to learn it, the challenges encountered and the supportive factors maintaining their engagement. Chapter Seven 'Gaining in a Landscape of Loss: The Value and Benefit of Mindfulness in End-of-life caregiving' distils the complex interwoven benefits of learning and using mindfulness whilst caring for a family member or friend at the end of life, and what this means.

Together these chapters honour how participants in this study spoke of their experience of mindfulness-based approaches in informal palliative caregiving. Specifically, to understand what mindfulness offers in this setting, one must first gain an understanding of the caregiving landscape and the process of learning mindfulness itself. Figure 7 provides a visual overview of how Part IV of this thesis is structured. This structure reflects the three overarching processes and their attendant categories identified in this study and which form the basis of the constructed grounded theory, to be detailed in Part V, Chapter Eight 'Discussion'.

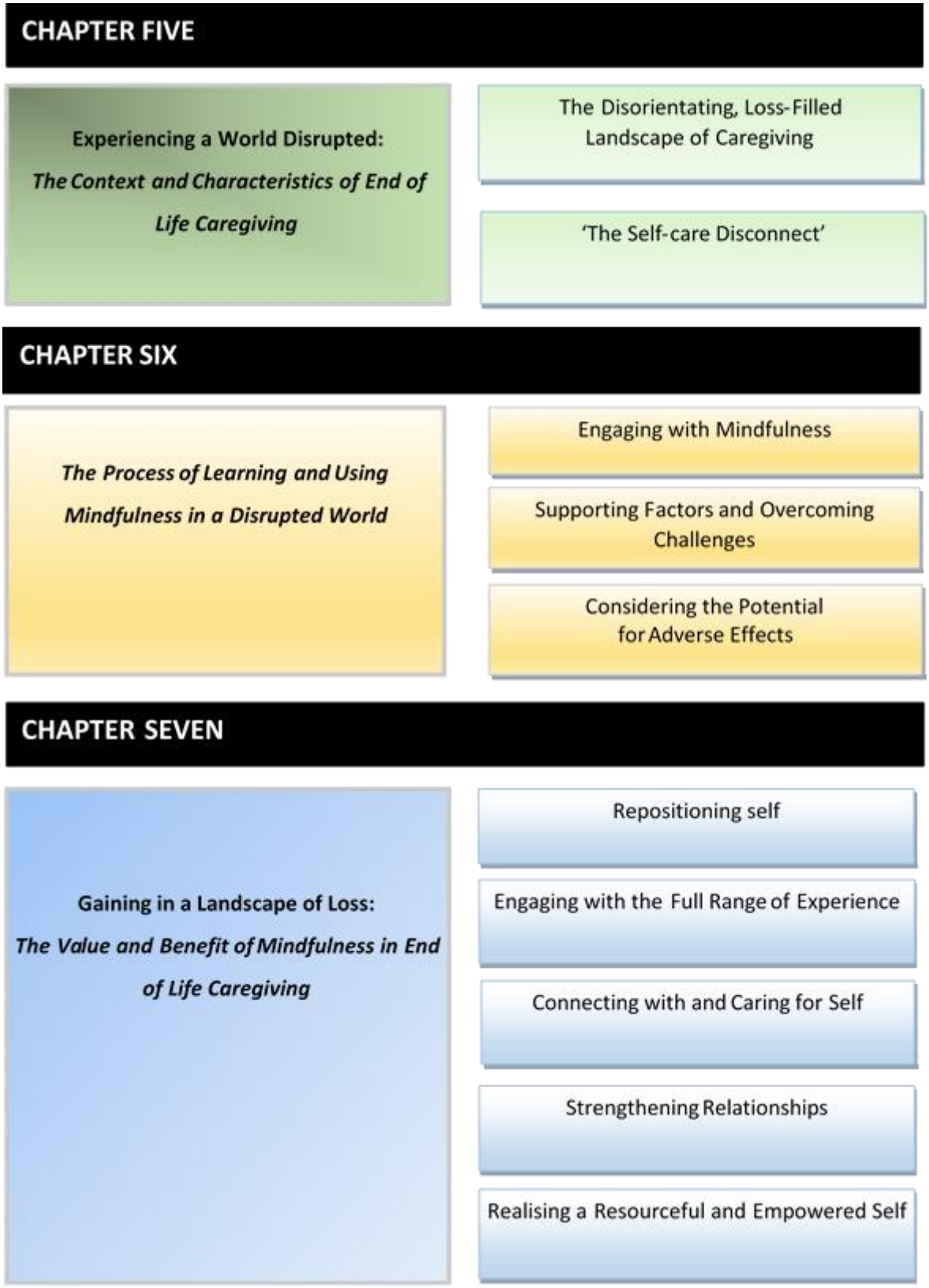


Figure 7: Overview of Findings Chapters

CHAPTER 5

'EXPERIENCING A WORLD DISRUPTED: THE CONTEXT AND CHARACTERISTICS OF END-OF-LIFE CAREGIVING'

5.1 Chapter Introduction

The previous chapter detailed the methodology used in this study to explore the experience of learning and using a mindfulness-based approach in end-of-life caregiving. Chapter Five is the first of three chapters reporting the qualitative findings of this study. It focuses on exploring the context and characteristics of informal palliative caregiving in the last twelve months of life. The chapter aims to provide a contextualisation for the remaining findings chapters which detail the process and the benefits gained from learning and using mindfulness in end-of-life caregiving.

The chapter is based around two conceptual categories. The first is entitled, 'The disorientating, loss-filled landscape of caregiving' and includes only caregiver data to provide the most nuanced insight into the caregiving experience. The second category, 'The self-care disconnect' provides further insights into the challenges experienced by caregivers by integrating data from both mindfulness facilitators and caregivers themselves.

5.2 The Disorientating, Loss-Filled Landscape of Caregiving

This first conceptual category depicts the experience of coming into and navigating the role of informal palliative caregiving. It is comprised of two key sub-categories. The first is 'Landing', which distils caregiver descriptions of arriving in an unexpected and disorientating world of caregiving, with the second subcategory 'Navigating difficult terrain'

providing more detailed insight into the type of challenges encountered and their substantial effect.

5.2.1 Landing

While all the caregivers in this study described their end-of-life caregiving experiences in different ways, a commonality amongst them was a pervasive sense of movement and disruption. All caregivers spoke of experiencing disruption variably described as being 'wrenched out' of a known and familiar world, or 'dropped into', or 'having landed into' a 'foreign' or 'alien' landscape, for which they did not feel prepared. This landing into the disrupted caregiver world stemmed, in all cases, from having a family member or friend diagnosed with an incurable illness and their role in coming to care for them.

Disorientation, bewilderment, or as Laura described, '*fumbling along'*, permeated descriptions of what it was like to land in the new landscape of caregiving. Many caregivers (Laura, Ava, Jason, Gwen) revealed a strong sense of surrealism associated with 'becoming' a caregiver. Ava, for example, conveyed complete disbelief when her husband was diagnosed with a terminal cancer. This event was unfathomable to Ava, who had already endured the death of a number of family members, including her mother, uncles and mother-in-law in recent years:

> *I couldn't cope with him being sick too. You know, why couldn't you get a cancer where they can just cut it out and keep going? Why did he have to have this horrible one, that's systemic? It's all wrong'(Ava).*

Molly, who was caring for her husband with end-stage heart and chronic obstructive pulmonary disease (COPD), relayed how she had questioned '*what is our life now*?' when

reflecting on the sudden disruption presented by her husband's condition. For Jason, who in his thirties experienced the sudden loss of his best friend, Matthew, there was a clear sense of bewilderment when he relayed the events of his friend's death, even struggling to speak in the present tense: '*He's my age - **was** my age.'* Gwen painted one of the most vivid descriptions of starting two years of caregiving for her sister as akin to being dropped into a catastrophic scene, describing that she '*was at ground zero.'* She further whispered, that her overall caregiving experience was *'a fucking nightmare',* conveying some hesitancy in voicing such a raw and honest appraisal of caregiving.

Despite the intense disruption to their lives and finding themselves in a surreal and disorientating landscape, caregivers still relayed a strong desire of '*wanting to be there*' (Sarah), so their family member or friend did not have to navigate their end of life journey alone. Ava talked about making the end of life journey with her husband as akin to climbing up the rock face of a mountain, uncertain and scary at times, but made better by the virtue of them doing it together: *'It's much better to climb up the mountain with Mark and look at the view with him, than stay at the bottom' (Ava)*.

5.2.2 Navigating Difficult Terrain

In addition to vividly describing their experience of landing in a place marked by disruption and disorientation, caregivers detailed the difficult terrain encountered in the caregiving landscape. They spoke of having to negotiate seven common challenges as they learnt to navigate through their new and unexpected caregiving reality. These challenges, explored in the following section, include: 'Dealing with diagnosis and treatment', *'*Confronting deterioration', 'Chasing and connecting to services', 'Redefining relationships and roles', 'Juggling', 'Engaging with death and bereavement' and 'Struggling to cope'.

Dealing with Diagnosis and Treatment

In describing their experiences of 'coming to' be a caregiver, the first two challenges, most commonly expressed by caregivers, were intuiting or being told of their significant other's palliative diagnosis and having to navigate treatment.

A palliative diagnosis was commonly described by caregivers as a defining point, whereby their life as they knew it, was first disrupted. It was from this point that their known and familiar world dissolved, and, in its place, the loss-filled landscape of caregiving emerged. However, caregivers shared quite diverse experiences of what it was like when their significant other received a palliative diagnosis. For example, three caregivers, (Ava, Gwen, Bill) emphasised the process as being very laboured or protracted. They all told of noticing new symptoms or drawn-out changes in their family member and described knowing '*something wasn't right.'* Gwen said that it was eighteen months before her sister secured a diagnosis, during which time she watched her sister become progressively unwell and have multiple trips to the Emergency Department at the local hospital. Similarly, Ava described '*just knowing'* over a considerable period that something was wrong with her husband, Mark. She explained in detail how she struggled to get a diagnosis for him:

> *His back was getting sorer, and he was taking more time off work. He never complains about anything, never, ever. Doctors were* [saying] – *"he was fine". He was having tests and stuff like that. I knew something was wrong.*

Ava then recounted, when travelling away to celebrate their wedding anniversary, she called an ambulance because her husband had deteriorated so much that he was unable to drive any further. Following presentation to hospital and her husband undergoing multiple

tests, Ava relayed being told that her husband had advanced staged cancer, with no prospect of a cure:

> *All his bloods were out, completely out. His haemoglobin was - there was nothing there basically. Everything was out…They said he had Multiple Myeloma. So, his whole system was riddled. He's got one normal disc in his back, all the rest had fractures in them.*

For Jason, the process of diagnosis and his emergence as a caregiver was short and sudden. Jason told how his best friend experienced a very unexpected and catastrophic medical problem, resulting in him becoming terminal and dying in a short amount of time:

> *Matthew had a heart attack. As a result…he had a hypoxic brain injury. So, he really died that night. He was resuscitated after 25 minutes, you know. He was resuscitated to brain death, really. So, he was admitted to hospital. He never regained consciousness...three weeks later, after being intubated, he died in a palliative care ward.*

These experiences of diagnosis, whilst varied, all strongly convey how diagnosis constituted the first challenge encountered by caregivers in their new disrupted world.

Following the experience of diagnosis, caregivers described encountering a new range of losses and difficulties associated with supporting their family member during treatment. Caregivers portrayed the different treatments undergone by their significant others as *'disturbing', 'distressing'* and '*horrendous',* particularly regarding the side effects. Other caregivers also reported querying the treatment decisions made by doctors for their family member. This represented a clear tension for many caregivers who appeared to be

torn between the preservation of their loved ones' lives and the support of interventions, treatments and procedures which they felt could cause more pain, discomfort and suffering. Lorna told of her 87-year-old husband's radical facial surgery. She vividly relayed the confronting and devastating impact of the surgery on his physical appearance, which she said changed the face she had known for many years. She also told of the negative impact of the surgery on his ability to undertake rudimentary movements such as eating and swallowing: '*He was very sick, and he had half his jaw taken away.*' Lorna also described questioning and negotiating clinical decisions around ongoing treatment for her husband. While initially, she felt she had little control or say in such matters, she spoke of 'coming to' advocate strongly against subsequent facial surgeries:

> *…then they were almost going to operate a second time and Paul (my son) and I said, "look no more of this". The doctor said, "we're pleased about that". I thought, well why the heck did you even think about it, and put it to us? (Lorna).*

Molly also spoke of doubting the benefit of continuing her husband's treatment who had end stage heart disease:

> *He is sort of getting to the end of the road in terms of things that can be done. He's been going up to hospital (1.5 hours away) for periods of time and having intravenous antibiotics. It works for a while. He gets better. He comes home feeling much better and immediately starts to go back to where he was and, in a week, or two weeks, he is back to where he was before. So, you start to think what is the point, you know?*

Molly's story also highlights the tyranny of distance for many caregivers in rural areas, particularly in accessing specialist treatment and care. Three rural caregivers spoke about

having to travel between three to seven hours round trip, to access treatment in larger metropolitan hospitals within Tasmania.

Confronting Deterioration

In addition to navigating diagnosis and treatment, caregivers spoke vividly about observing the deterioration of their family member or friend and having to confront the reality of their situation. Caregivers described what it was like to watch someone they cared about, incrementally lose health and vitality. Laura described lying awake at night, unable to sleep, listening to her husband's changed breathing:

> *…his breathing too is getting really, really shallow. I don't know that he notices that...but yeah, I can notice that when we go to bed – and everything is really quiet, I notice how shallow his breath is.*

Caregivers also talked about observing the loss of their family member's ability to engage in previously undertaken activities and a retraction from the person they used to be in the world. Molly detailed how her husband had deteriorated in a period of months, '*You know a couple of months ago he* [Peter] *could walk up the back but he can't now… he can barely walk from room to room.'* For three caregivers (Lorna, Ava and Molly), the failing health of their husbands and the cascading effects of this deterioration, led to them experiencing another form of loss. For all three women, this loss related to the home they shared with their spouse and their difficulty in maintaining it on their own. For Molly, it was a constant challenge for her to assume the additional tasks that her husband previously undertook in the relationship to maintain their property:

It is a lot of work… We have got this great, big block up here with chooks and pigeons and I have to look after them and the vegie gardens and fruit trees. It is a big block and it is a big house for just the two of us and we have a wood fire and so there's wood to bring in. It's not set up you know [long pause] *it is set up to be for the two of us, and now it is just me.*

Lorna told how she and her husband had sold their loved rural property to seek a more manageable and supported housing option following her husband's deteriorating health and cancer progression. Lorna explained that, whilst this move was difficult, her sense of loss was mediated by gaining more support in her caring:

We knew we had to. People said the same to us, our friends, don't leave it too long. It will just be terrible when you do have to move. So, we took that on board and we thought well, we've got to go. It was the best thing we ever did really... here you can just ring the phone or press the bell, and someone will come down and pick him up off the floor or whatever had happened…Any hour of the day or night.

For caregivers, observing the deteriorating health of their family member also involved the need to confront the reality of their situation and the inevitable loss of life, as they knew it. This also included the loss of future-plans, communicated by some caregivers, such as Molly, as having been 'robbed' of a life that they had intended for themselves:

Peter and I were planning to have this trip to Italy, but we couldn't go because he was too sick yeah, and so yeah. I've got that money sitting aside and I will go one day, even if I can't go with him (Molly).

Whilst caregivers spoke of noticing and wrestling privately with the sense of loss unfurling from the deteriorating health of their family member, it was clearly difficult for them to confront the full reality of their situation. Specifically, caregivers spoke of finding it too challenging to talk with the person for whom they were caring about issues of prognosis and end of life. Laura explained that, whilst she greatly wanted to talk with her husband, Scott, about the terminal nature of his Motor Neuron Disease, she was unable to do so because he preferred not to talk about it. Laura respected her husband's preference not to give voice to the reality of their situation, but acknowledged openly it had been 'trying', and had led to considerable emotional strain:

> *We sort of fumble along and pretend that everything's going to be fine and we talk about holidays next year and what we're going to do with this and what we're going to do with that, when the reality of it is, that, yeah those things won't happen. So that's what Scott does. So, I sort of just follow his lead and he doesn't – sorry* [begins crying] *…He doesn't like talking about it.*

For Molly and her husband, Peter, acknowledging and talking about the reality of Peter's deteriorating health was similarly described as being '*too big'* and '*too hard'*. Molly perceived that she would soon need to 'face' their situation but was choosing to delay this for now: *'Sometimes I think we are just not facing the reality but anyway, one day we will...Yeah we might do that one day, but we don't have to worry about that today'.*

Chasing and Connecting to Services

Another challenge encountered by caregivers in this study was negotiating the unfamiliar terrain of connecting to support services. Caregiving appeared to be largely undertaken without the support of available services. This appeared to be associated, in

part, with a strong expectation or sense of feeling '*responsible for everything'.* Caregivers spoke of carrying the expectation of being able 'to control', 'to fix' and make things better for their terminally ill family member or friend. Feeling responsible for everything in caregiving also involved a projection of 'being strong' for the benefit of others, even when caregivers felt the opposite: struggling and vulnerable. When caregivers were unable to 'take care of everything' or 'be strong', many spoke of experiencing distress, loss of agency and sense of control. Gwen shed light on her experience when she spoke of trying to influence the care provided to her sister in hospital:

> *I can't control what's going to happen to her. I can't control what the doctors do. I can't control how the nurses look after her. I can't control anything.*

Jason spoke of projecting strength for the benefit of others, even describing himself as a 'rock' for others. However, he recounted a poignant moment when his strong façade crumbled in front of a friend, who was shocked to see him so emotional in the face of anticipated loss:

> *I'd stepped outside* [of the hospital] *and I was in the doorway and one of the guys came out to have a cigarette. The look on his face was just horrible because I think until that point he'd seen me as this rock…so he was seeing me crying…I mean, he had accepted that Matthew was going to die but it was more like, fuck, even Jason's rocked by this now.*

Inevitably for many caregivers (Jason, Laura, Gwen, Molly) the projection of strength for the benefit of others made it very difficult to admit that they themselves needed support to care for their family member or friend. At the time of interview, all four caregivers (Molly, Ava, Laura, Gwen) who were currently caring, had yet to connect with services, '*At this*

stage we don't have a hell of a lot of support' (Laura). Many caregivers used the phrase, '*It's just me',* to emphasise that they were largely on their own caring for their family member. Caregivers commonly spoke of being 'unsure' and having little awareness or familiarity with the 'web' of services available to support them in their caregiving role. For some, there was a clear lack of knowledge around what was available to them, regardless of their need or circumstances. Molly, for example, understood that support services were not available to her because she was 'physically capable' of looking after her husband: 'So*, I don't know really what services are available for someone in our situation, because I am able-bodied and it's not like I am old'.* Caregivers also detailed their attempts to engage services, with many speaking of '*missed connections*' (Ava, Laura, Gwen). Laura spoke about the process and amount of time it had taken her to enquire about services, describing it as 'a chase': '*Oh God I've spent so long chasing, chasing, chasing'*. She talked about enduring slow responses to requests for information and referral and her frustration when health professionals contacted her husband when she had been at work, and therefore, unable to be part of the communication. Ava spoke of being offered social work support multiple times throughout her caregiving experience, but referrals were never actioned:

> *When mum was in the hospital they offered us a social worker and we asked for it and it didn't happen. When Mark was first diagnosed they offered us a social worker and it never happened... I reckon five or six times. It's never happened, and we've said, "yes please" every time.*

Along with trying to 'comprehend' and 'chase' what services were available to them, other caregivers (Sarah and Laura) spoke of encountering resistance to services from the person for whom they were caring, which delayed access to much needed support. Laura

explained that, whilst her husband had initially agreed to support services assisting him whilst she was working, he then refused to allow them into the home, leading her to have to cancel these arrangements before they had even begun:

> *He hit the roof…I honestly thought we'd discussed it all and he was fine with it, but like I said, his memory is not real good and I don't know whether it's the realisation that he really needs it but he's just being stubborn or doesn't want it.*

Laura further admitted she had kept from her husband that she was seeing a counsellor to cope with her own emotional turmoil and grief, largely because he did not believe in support services of any sort:

> *Scott doesn't know I've been seeing a counsellor…I don't think he'd deal with it very well if he thought that I wasn't dealing with it very well. He feels that he's very happy that he can lean on me and that I'm strong...*[crying].

Across all caregiver experiences, connection to services appeared to happen late in the illness trajectory. For example, the caregivers whom had lost family members at the time of interview (Bill, Jason, Lorna, Sarah) all relayed having only accessed or been offered formal services and support such as palliative care or community nursing, *'towards the end*' (Bill) and arguably 'too late'.

Redefining Relationships and Roles

In addition to navigating diagnosis and treatment and the difficulties in securing services and support, a fourth challenge commonly experienced in the caregiving landscape was 'redefining relationships and roles'. Caregivers spoke often, in-depth, about coming to terms with themselves as 'a caregiver' and the tension this provoked. There was a general

division in how caregivers experienced and made sense of their new role. For example, there was either a resistance to or adoption of the role and identity of 'carer'. Five participants, (Gwen, Molly, Laura, Ava, Lorna) adopted the view of themselves as a 'carer'. They emphasised that this was a process, of 'accepting', 'becoming' or 'growing into' the carer role over time by virtue of 'living it':

> *I am starting to see myself as a carer. It hasn't been how I felt about myself. I just thought, you know, I was a wife, but now I am beginning to see that I am a carer…You know, day by day…the more you do, in the role of carer, the more the word, you know, fits* (Molly).

For a number of caregivers (Molly, Laura, and Gwen), the movement towards perceiving themselves as 'a carer' was precipitated by a heavily felt sense of loss or retraction of their own independence, due to the escalating support requirements of their significant other. Laura explained the catalysing events underpinning her identification as carer of her husband, who had Motor Neuron Disease:

> *I don't think I've really identified as a carer until probably the last three or four months. The fact that I can't go away for a night anymore, without there being some big issues. Now that it's got to an extent where it's where it is…He can't get his clothes off. He can't get socks on. He struggles to feed himself* (Laura).

Three caregivers in this study (Bill, Sarah, Jason), never identified or willingly described themselves as a carer. Bill firmly stated that he perceived his role only as 'husband' to Beth, supporting her in the final chapter of their sixty-eight years of marriage: *'No, I didn't see myself as a carer. Not at all…I would describe my role as someone trying to make life easier for her'.* Sarah emphasised that whilst she was familiar with the terminology of 'carer,'

because of her professional background as a doctor, she never identified herself with the term. Sarah explained that she was there in the role and capacity of 'daughter', to support her mother at the end of her life: *'I don't know that I would have called myself a carer. I would have called myself a daughter*'. Similarly, Jason, did not perceive his role as carer, but rather as a 'best friend'.

Regardless of whether caregivers perceived their role as 'carer' or as a continuation of a relationship dynamic, supporting a family member or friend with a palliative illness was described as invoking a profound disruption to relationship boundaries and expectations. For all caregivers, the failing physical health of their loved ones and the subsequent need for support was spoken about as invoking a profound sense of loss, especially in unsettling the 'normal' division of roles, responsibilities and routines within existing relationships. In some cases, these roles and responsibilities had been established over the course of decades and had come to mark the nature, quality and continuity of close relationships. Caregivers described that the complex facets and demands of caregiving caused these relationships to be redefined and roles to be reluctantly surrendered, which wasn't always easy on top of the reality of a palliative diagnosis:

> *What is my responsibility and what is not my responsibility? That's a blurry thing isn't it, with a sick person?…I don't want to do things for him that he can do for himself, because that wouldn't be good for him and it wouldn't be good for me* (Molly).

Caregivers who had a health professional background (Ava, Sarah and Jason) spoke of encountering additional complexities regarding boundaries in relationships. They spoke of having two selves, professional and personal, which impacted on their own experiences of caregiving, as well as how others perceived their role. For all of them, balancing their

professional expertise with their personal roles, as siblings, friends, partners and children, was undeniably challenging. Ava talked about how during the care of both her husband and mother, family and health professionals alike had unrealistic expectations of her because she was a nurse: '*I said to one of the nurses, "I'm his wife. I'm not a nurse". Don't make me the nurse'*. In another poignant example, Ava shared how she was expected to be the nurse, as opposed to a grieving daughter in the moments after her mother died, which only amplified her sense of overwhelm and loss:

> *When it came to preparing mum's body* [crying] *we'd been doing all mum's care I said to the nurse, "I can't". She said, "I'll leave you to it". I said, "I can't do it, I need help, you have to* [long pause] - *I can't". My sisters, yeah they just expect you to be able to do it.*

Jason used the words '*divorcing clinician from self for a moment*' to explain how he moved in and out of the professional (clinical psychologist) and personal roles, while he sat beside his best friend who was on life support for three weeks before his death.

A number of caregivers also gave voice to experiencing a loss of connection with the person for whom they were caring; an experience that was underpinned by different reasons. Lorna, Gwen and Molly, described periods of 'pulling away' from the person they were caring for because of their frustrated and difficult responses towards them as caregivers, and the illness itself:

> *He's really sick, but as well as being really sick, he has got this attitude to being really sick...and he is very angry and upset about being sick and um you know, rails (sic) against it* (Molly).

Ava spoke about realising that she had disconnected from her husband because of a desire to protect herself from feeling the grief and loss of his terminal diagnosis and anticipated death, which she later reflected regretting. It was clear that the shifting relationships, roles and responsibilities and their view of themselves in caregiving, constituted a significant challenge for caregivers to navigate in their new landscape.

Juggling

The fifth challenge detailed by caregivers involves the theme and metaphor of 'Juggling'. In telling their stories, caregivers commonly situated their caregiving in the context of and profoundly shaped by, other simultaneous life events, as well as existing roles. For example, Sarah came to care for her mother at the same time as becoming a mother herself for the first time. Bill assumed the role of supporting his wife at home following her terminal cancer diagnosis, while trying to manage the worsening symptoms of his own Parkinson's disease. Gwen recounted coming to care for her sister, at the same time as she was caring for other family members and friends who were vulnerable and unwell. Ava was caring for her husband against an extraordinary background of experiencing the recent deaths of three significant family members, having a life-threatening health situation herself, and moving interstate to support other terminally ill and bereaved family members.

All the caregivers interviewed in this study found it difficult to manage the new tasks and challenges of caregiving, on top of existing life demands. They voiced that such a 'balancing act' required both organisation and adaptability. Laura, who was caring for her husband following his declining health said, '*I am trying to juggle too many balls at the moment'.* She explained both the act and the consequences of balancing full-time work, parenting her 11-year-old son and caring for her husband:

> *Well I get up. Get my son ready and off to school. I go off to work. Come home. Go to school sports with him* [son]. *Come home. Get tea ready. Clean up. Put Scott in the shower. Get him sorted. It's nine o'clock before I'm sitting down on the couch, and the first time in the day that I've stopped.*

Sarah also spoke of juggling multiple roles and responsibilities as a doctor, a wife, a parent to her new baby and as a daughter to her ailing mother. She explained taking extended leave from her work and temporarily moving interstate to care for and support her mum, acknowledging that managing these activities was difficult, but important:

> *Catching the bus every day with a pram and trying to get my baby to sleep so I could talk to my mum…It was hard, but it was nice to be there …Lovely to have that, you know, he got time with her and she got time with him as well* (Sarah).

Engaging with Death and Bereavement

'Engaging with death and bereavement' constitutes the sixth challenge outlined by the caregivers in this study regarding navigating the difficult terrain of caregiving. In addition to encountering the multiple, loss-infused challenges encountered throughout the life of the their significant other, caregivers openly shared how they experienced the death of the person for whom they were caring. At the time of interview, four caregivers (Bill, Lorna, Sarah, Jason) had experienced the death of their family member or friend. Death was variably described as 'a release' or a 'dark experience'.

Death was described as 'a relief' by the three caregivers (Bill, Lorna, Sarah), two of whom were the most elderly of the interview participants. Bill expressed his feelings about his wife's death: '*When she died it was a great sense of relief for both of us… she was in a lot*

of pain and she couldn't handle anymore of anything'. Bill recounted his experience of his wife's death at home as peaceful and in keeping with the way his wife approached her life, with courage and without a fuss:

> *She passed away here on this day bed here…* [teary and points to the day bed by the window overlooking the garden] …*Yeah, she just went to sleep after lunch and left her consciousness and lived for another five hours or six hours – well almost six. Michelle* [his daughter] *was with me. All the friends said, "That's typical Beth, no fuss, quality behaviour".*

Jason's experience of his friend's death was different again, in that it was untimely and sudden. In effect, Jason described facing two deaths. The first was at the point of realising that his friend had suffered a clinical brain death and the second when his body stopped breathing. Jason used the phrase, '*All this dark shit that happened',* in his account of these experiences and described things he had not previously spoken about, confronting moments outside the realms of anything he had experienced before: '*He was a big man and so he didn't fit in the body bag. I helped put him in the body bag'.* Jason also experienced conflicting emotions around the death of his friend, both feeling proud to have supported his friend's children to say goodbye to their Dad, but also feeling a gut-wrenching sense of grief:

> *After he died, I shaved his head because he had a three-year-old and five-year-old and yeah...He was a bald bloke. But in the three weeks he had grown some side stuff and the girls didn't want to see their Dad because he looked different with the hair.*

Whilst describing these experiences was clearly difficult for Jason, he indicated it was helpful for him to talk about them for the first time, as he had not yet been able to share them with others.

Beyond talking about the actual death of the person for whom they were caring and surrounding events, caregivers also emphasised that their experience of grief *'continues to be massive'* (Jason) and that adjustment to life after their family member or friend has died, has been an ongoing process, not something that ceases: '*I will probably grieve for her until the day I pack it in myself*' (Bill).

Struggling to 'Cope'

The conceptual category, struggling to 'cope', constitutes the final commonly encountered challenge in the end-of-life caregiving landscape described by the caregivers in this study. A deep-seated concern about their ability to 'cope' with the enormity of the caregiving role and to navigate its myriad of challenges, permeated caregiver narratives. Caregivers spoke about often getting 'caught up in' and 'lost in' their projected fears of the future. In this way, many expressed a concern about not only managing the present tasks of caregiving, but also how they might meet increased demands when their family member or friend became increasingly unwell:

> *You know the idea is that Peter's got a chronic disease. He is not going to get better. He's - it is going to get worse and that is scary because you know you're not managing now, so what is it going to be like if it gets worse? (Molly).*

Both Lorna and Bill reflected on how, during caregiving, they also carried a heavy concern about not being able to cope with caregiving and, in particular, their spouse's death. Bill

reflected, '*I was dreading her departure because I thought I won't be able to handle it'*. Lorna similarly remembered continually questioning her ability to cope with her husband's death, '*How will I be when he dies?* Other caregivers, like Jason, described the experience of his friend's death and the grief that followed as profound: '*I think unequivocally it's definitely been the biggest event to have occurred in my life'* and one that has drawn heavily from his personal resources to navigate. A sense of being alone or unsupported amid such challenging experiences, '*It's just me'* (Laura), appeared to compound caregiver concerns about coping, '*they are big things to sit with and sit alone'* (Gwen).

As caregiving was situated within the occurrence of other demanding life events, caregivers also spoke of experiencing a sense of overwhelm at times. They described feeling depleted, '*vulnerable*', '*a mess'* and '*on a cliff's edge'*. Laura spoke of how being enmeshed in caregiving had the negative effect of subsuming all elements of her life. She explained that she tried to wrestle back a sense of being more than a carer to her husband, by not talking about caregiving to her friends:

> *I stopped because I felt like it was all I was ever talking about. I felt that when I - in the early days when I did catch up with friends, it would consume our conversations. It defined - it felt like it was defining me. That's all that there was.*

Caregiver narratives were heavy with feelings of vulnerability and weariness. They spoke of being consumed by and under-resourced in their caregiving experience. Whilst caregivers spoke of needing to project a sense of coping for the benefit of others, as pointed to earlier in this chapter, these findings demonstrate, the projected face of coping did not ease what many caregivers conveyed as an acutely felt sense of vulnerability and concern that, '*I can't do this*'.

The findings presented in this chapter so far have covered the first conceptual category entitled 'The disorientating, loss-filled landscape of caregiving'. The key challenges requiring negotiation in this landscape have included: 'navigating diagnosis and treatment', 'confronting deterioration', 'chasing and connecting to services', 'redefining relationships and roles', 'juggling', 'engaging with death and bereavement' and 'struggling to cope'. The next section presents findings related to the second core category entitled: 'The self-care disconnect'.

5.3 The Self-care Disconnect

This section presents the prevalent finding of caregiver reluctance to consider and take care of oneself and ones needs in caregiving. It does so through the conceptual category of 'The self-care disconnect', using both caregiver and facilitator narratives, as this finding was deeply embedded in both data sets. The factors informing the 'The self-care disconnect' will be described, including, 'The perceiving of self-care', 'Messaging about self-care', 'Feeling invisible', and 'Delaying self-care' along with the perceived consequences for caregivers if they are not able to consider or seek support for themselves and their own needs.

Despite the disruption to normal life and the heavy losses and challenges of navigating the difficult caregiving landscape, caregivers were very reluctant or resistant to think about or take care of themselves and their own needs: *'There's resistance to self-care'* (F 12); '*No it's not something that I consciously think about – what I need'* (Laura). Caregivers spoke about, and were observed by facilitators to commonly adopt, an overwhelming, if not complete focus on the person for whom they were caring. This

tunnelled focus was perceived to come at the cost of caregivers readily neglecting their own physical and mental health:

> *Carers usually will focus completely on the patient and neglect their own health. Many of them will stay with the patients overnight, and if the patient cannot sleep they also won't sleep, and if the patient is sad they also feel sad …Sometimes they don't think that their own stress needs to be taken care of* (F 11).

Both caregivers and facilitators perceived several factors underpinning caregivers' reluctance to consider and take care of themselves and their own needs, each of which are discussed below.

5.3.1. The Perceiving of Self-care

In the context of end-of-life caregiving, self-care was spoken about by both caregivers and facilitators in terms of 'taking time' for self, which was observed to invoke a profound tension for caregivers. Firstly, 'taking time-out' to care for themselves was perceived to violate their strong sense of responsibility to provide care for their terminally ill family member or friend. For example, it would mean entrusting or discharging care to others in their absence, something that most caregivers sought to avoid:

> *They might not necessarily trust that they* [other family members] *would know what to do - or even volunteers that are offering that service. It's sort of a self-belief in their own ability to handle something is much higher than in anybody else in the same situation* (F 12).

Secondly, the idea of 'taking time' and by extension, attention, away from the person for whom they were caring was perceived as fundamentally selfish. To focus on caring for themselves in such a context therefore, induced a heavy sense of guilt:

> *It's about recognising the intensity of the carer's role through the experience of their partner dying or their family - their mother or father dying. It's so incredibly intense that every moment matters…Their sense of looking after themselves is not a priority to them* (F 3).

Caregivers also had a heightened concern not to be absent for the death of the person for whom they were caring because they were afraid *'to miss the final moment'* (F 11).

5.3.2. Messaging About Self-care

Wider cultural messages about self-care, outside of the caregiving context, constituted another factor underpinning the 'self-care disconnect'. For example, for most of the caregivers in this study, the value of taking care of themselves and their own needs was not a message they had received in their lives more broadly. This had strongly influenced their prioritisation of others' needs and their reluctance for self-care within the caregiving experience: '*I have never focused intently on my personal needs'* (Bill). Four participants (Ava, Lorna, Bill, Laura) referenced family norms and upbringing as the foundation of considering others' needs first:

> *I think I've grown up with that, that you give to others and that's me always…do everything for everybody else before you do anything for yourself* (Ava).

Laura explained an outward concern for and responsibility to care for others were embedded in her childhood:

> *… I think I learnt that from my parents. Both worked long hours and six, seven days a week. In Grade 3, I used to walk my brother to school, bring him home, turn the tea on so tea was ready at six when mum got in the door and we had chores -that was just the way it was.*

In the context of end-of-life caregiving, participants viewed that this message of '*other people's needs come before our own*' (F 10) becomes amplified. Facilitators cited observing strong influences of cultural values on caregivers' 'tunnelled' focus on '*caring for their own*' (F 2), to the detriment of their own needs. Gender was observed to shape caregivers' views and practice of self-care. One facilitator had observed female caregivers were most challenged by the practice of extending care towards themselves, and emphasised the implications that this 'Self-care Disconnect' had for their wellbeing:

> *We've all been mothers - most of us, not all of us - but many of us have been mothers or aunts, we have dragged ourselves out of bed at two o'clock in the morning when we're sick and dying to get up to a crying child. We know what it means to put our own needs somewhere else and just look after somebody…but you can only do that in a crisis, you can't do that in a sustained way* (F 4).

Molly was the only caregiver in this study who spoke about having a strong focus on taking care of herself and her own needs in caregiving and in life more broadly. When asked how she had been able to have this focus, she explained:

> *Well you know a life-time of being a Feminist I suppose, Yeah.* [laughs]…*I was a women's liberationist right back in the 1960s and 70s when you know we were women libbers, burn the bra and all that. Yeah you know that's been a guiding force in my life. We women needed to look after our own needs and sometimes you know*

> *put yourself first and not be subservient. And all those messages about what women should do in terms of caring for others I have um, I've questioned, so that's allowed me to have a very strong sense of my own needs, always, I think.*

However, even for Molly, instituting self-care in the context of caregiving was experienced as challenging.

5.3.3. Feeling Invisible

In addition to individual perceptions of self-care in the context of informal palliative caregiving, and messages received about self-care more broadly, another underpinning factor of 'The self-care disconnect' was the sense of feeling invisible. For example, caregivers' experiences and needs received little focused attention by others: '*I don't remember there being a big focus on my needs*' (Sarah). This absent focus appeared to reinforce a view that caregiver needs were not a legitimate concern, even amongst those who were being cared for:

> *I think, I mean he's* [husband] *quite self-obsessed, which is understandable considering he's in so much discomfort a lot of the time. I don't think he thinks about me too much at all actually. Hmm. Except in as far as whether I am here or not* (Molly).

Encouragement by friends and family for caregivers to consider their own needs and institute ways of taking care of themselves was also reported to be rare. Laura explained her friends and family asked about her needs in a polite, but rather veneer way, to which she had learnt to respond with a veneer answer:

> *People ask me: "How are you"? – "Yeah good" - "How is Scott?" - "Yeah good"* [strained laugh]. *"Do you need anything?" – "No thank you".*

Similarly, health professionals were perceived by most caregivers to not focus on carer needs at all, thus making them feel 'invisible'. Sarah explained that staff at the palliative care unit caring for her mother were 'available' to talk with. However, proactive enquiring about her needs, was not something that occurred as part of normal palliative 'care'. Lorna was the one caregiver able to provide an example of health professionals focusing on her needs. However, this attention only eventuated in response to Lorna reaching a 'crisis' point:

> *At* [the private hospital], *they could see that I was in such a mess that they couldn't send him home to me. So, they talked to the doctor and a wonderful woman up there who dealt with that sort of thing…They just spoke to him and said, "look, we can't pass you for going back home. You need more total care"* (Lorna).

Lorna further spoke about experiencing a huge sense of 'relief' that someone had recognised and advocated for her needs as a carer and sought agreement for her husband to go into a high care facility.

Many of the mindfulness facilitators came to reflect on their own health-care practice and services. Most acknowledged lacking a strong focus on rendering any support to caregiver needs. One facilitator working in a cancer-based setting conceded **'***carers sadly, I'm well aware, take a backseat'* (F 2). Another commented that, whilst the philosophy of palliative care advances caregiver support, this does not generally occur and certainly not in a structured way. He spoke of the type of support offered to caregivers within his work

context of an inpatient palliative care unit, explaining it was predominantly informal and reactive, as opposed to an intentional, targeted or embedded part of routine care:

> *Usually it's not the intention to see the family member…when they come to visit the patients and if they look like they are very stressed we might like just pull them aside and sit down and try to explore that* (F 11).

As a result, facilitators expressed that many caregivers come to view themselves not as a separate person with their own needs to be cared for as part of a wider dynamic, but as an extension of the care system.

5.3.4. Delaying Self-care

Participants reflected that the multifactorial underpinnings of caregivers disconnect with the concept and practice of self-care, ultimately led to an approach of '*delayed self-care'* (F 12, 9). That is, caregivers delayed caring for themselves and their own needs, until the person they were caring for was more stable or alternatively had died. One facilitator, working in palliative care, had observed caregivers to make sense of deferring self-care in the following way:

> *They come from the perspective of, well, that's - my role is to care at the moment, so I'll do that 100 per cent and then, when I'm no longer needed in that role and the person has died, then, I'll care for myself. So, it's this delayed self-care that they have the attachment to* (F 12).

Caregivers shared their own experiences of delaying self-care. For example, Laura talked about attending to her own physical health, including exercise, when she is no longer in the caring role. In another poignant example, Ava spoke of postponing much needed surgery on

a broken foot until her husband's situation was more stable: '*One of them* [foot] *is broken and still waiting for a pin in it, but I can't do that until Mark is better'.*

In the experience of a number of caregivers in this study, reaching a 'crisis point' that significantly threatened their own mental health and the sustainability of caregiving was the only thing that seemed to puncture this strong resistance to and decision to delay self-care:

> *I got to a state where I was so empty I had to do something* [unclear] *because I didn't have anything left to give, to the state where I was shutting my own husband off. How bad is that?* (Ava).

> *I feel like I'm fine until I'm not. It's when I get to that point where I just - yeah, I feel like a bit of a basket case. Something will happen, and it will only be something small, and the emotions will start. I'll start crying and I can't stop, and I won't want to be around anyone. I won't want to see anyone. Once - yeah it's once I've got to that point that I look at what I need* (Laura).

Caring for themselves seemed more accepted, although still uncomfortable, for caregivers if it was perceived to support and sustain the care of their family member or friend. Participants voiced that this deeply embedded self-care disconnect had significant implications not only for caregivers' own health and wellbeing, but also in terms of developing and garnering caregiver participation in programs that support thinking about and taking care of themselves and their own needs.

5.4 Chapter Summary

This, the first of three results chapters in this thesis, has provided insight into the experience of end-of-life caregiving as akin to being torn from a known and familiar world and dropped into a disorientating, loss-filled landscape. It has contextualised and highlighted a range of common challenges encountered by caregivers including, securing a diagnosis, navigating treatment, confronting deterioration and the reality of their situation. Redefining relationships and roles and coming to terms with their sense of self in caregiving were also detailed as common challenges. Additionally, caregivers voiced encountering multiple losses and juggling an array of roles and demands, that often felt 'too many' to hold on to by themselves. Whilst feeling responsible to lead and 'make things better' for their significant other in their new reality, caregivers expressed a heavy concern of not being able to cope, feeling under-resourced and alone at times in navigating the unfamiliar terrain of caregiving.

The findings presented in this chapter have also revealed that despite the obvious tensions and demands of caregiving, caregivers experience a profound disconnect with the practice of taking care of themselves and their own needs in caregiving. A full focus on the care recipient, the ascribed meaning of self-care as selfish, feeling invisible and broader cultural messages about putting others first, underscored this self-care disconnect. As a result, self-care is delayed until bereavement or until a crisis point is reached.

The interviews aimed to explore both positive and negative aspects of caring, however, positive aspects of caregiving were not a strong feature in the narratives of the caregivers in this study. Instead, caregivers in this study detailed in frank and wholehearted

ways, the considerable challenges and darker moments navigated in the caregiving landscape: a disrupted, disorientated world, characterised by loss.

The next chapter builds on this landscape to explore the process of learning and using mindfulness in this difficult context of end-of-life caregiving. It explains how caregivers navigate from a disrupted world into a decision to learn mindfulness, what this looks like, the challenges encountered and the supportive and enabling elements that support engagement and benefit.

CHAPTER 6

THE PROCESS OF LEARNING AND USING MINDFULNESS IN A DISRUPTED WORLD

6.1 Chapter Introduction

The previous findings chapter presented the first overarching process 'Experiencing a Word Disrupted: The Context and Characteristics of End-of-life caregiving'. This second results chapter presents 'The Process of Learning and Using Mindfulness in a Disrupted World', as the second overarching process identified in this study. Integrating the views and experience of two sets of participants, caregivers and mindfulness facilitators, it comprises three key categories: 'engaging with mindfulness', 'supporting factors and overcoming challenges' and 'considering the potential for adverse effects'.

6.2 Engaging with Mindfulness

The first conceptual category of 'engaging with mindfulness' distils the way in which caregivers come to learn mindfulness within the disorientating and loss-filled landscape of end-of-life caregiving presented in the previous chapter. This section explores what learning mindfulness entailed in this setting and the factors supporting caregiver engagement. It comprises two subcategories. The first is 'coming to learn mindfulness' and the second is, 'readiness, motivation and the catalyst of crisis'.

6.2.1 Coming to Learn Mindfulness

The caregivers in this study predominantly received information about mindfulness and avenues for learning it, via 'word of mouth' from 'trusted sources' such as family and

friends. In all cases, these 'trusted sources' had either experienced benefit from mindfulness themselves or had known others who had. These 'trusted sources' actively encouraged caregivers to learn mindfulness, to help them manage the demands and stressors of caregiving. All caregivers acknowledged that this had heavily influenced their willingness to engage with mindfulness. Additionally, these trusted recommendations helped temper some initial hesitation for six of the caregivers (Ava, Bill, Gwen, Molly, Laura, Lorna) who were learning mindfulness within the context of actively caring for their family member. For example, Molly told how a friend of hers, *'had discovered this phone app and she recommended it and so I signed up'.* Lorna explained that a close friend had told her about Max, a psychologist and mindfulness practitioner. Her friend had recommended mindfulness because she *'had a good experience in America with someone like him so ...I thought that sounds good'*. In addition to suggestions from family and friends, some caregivers (Ava, Laura, Gwen and Molly) also described a larger sense of trust in 'fate' or a higher power having brought mindfulness into their lives to help them cope with their harrowing new landscape and challenges of their disrupted caregiving world. Molly said, '*it was meant to be'* (Molly) with Laura similarly stating, '*I don't believe in coincidences, so I thought, yeah, it was time to start*' (Laura).

Beyond family and friends as key sources of information, it was perceived as rare, by both caregivers and mindfulness facilitators, for health professionals within palliative care or across the care continuum, to directly refer caregivers to mindfulness programs or practitioners. Bill was the only caregiver in this study to be referred to a MBI by a health provider, his neurologist, because he had observed other clients gain benefit from mindfulness. In exploring the apparent lack of referral of caregivers to mindfulness, some facilitators explained that within the palliative care setting in particular, mindfulness was

considered to be relatively new and a very different approach to the accepted biomedical paradigm of care: *'I think it's still early days, and I think it's a bit of a buzzy word'* (F 5).

Based on their experience, mindfulness facilitators reported that the most likely way for caregivers to receive information about and the opportunity to learn mindfulness, was through existing contact with a health provider who had training in mindfulness and offered to teach them. Most often, this occurred as a result of seeing a counsellor or mental health practitioner who offered to integrate mindfulness training into the therapeutic encounter. Eight facilitators (1,3,5,7,10,11,12) spoke of teaching caregivers mindfulness in this context. One facilitator explained her process of inviting caregivers to learn mindfulness in the context of a counselling relationship:

> *Sometimes it seems to emerge, - as you make your assessments and start talking, that it* [mindfulness] *would be helpful. I guess because I feel that it always can be helpful, I would always talk about it and most people are interested* (F 5).

There was a view, particularly among facilitators, that an established sense of trust and rapport was important for caregivers to feel '*safe and willing'* enough to learn something new within such an intense and time-constrained landscape as end-of-life caregiving: '*most of the time you need a few sessions … to have the rapport first'* (F 11). For Laura, who was offered the opportunity to learn mindfulness not by referral, but as part of her sessions with an existing counsellor, similarly explained that her early sense of vulnerability was alleviated by learning mindfulness within a safe, supported relationship:

> *By the time she'd got through it a bit* [guided mindfulness exercise] *I was completely focused on what she was saying and doing exactly what she asked, I felt supported* (Laura).

In exploring how caregivers came to learn mindfulness, within the difficult landscape of caregiving, it was clear that information and encouragement from trusted sources were critical.

6.2.2 The Catalyst of Crisis, Caregiver Readiness and Motivation

Additional underpinnings of caregiver engagement in mindfulness, identified in this study, were the catalyst of crisis, caregiver readiness and motivation.

In exploring caregivers' engagement with mindfulness, one of the most striking findings was, that for most of the caregivers interviewed (Ava, Gwen, Laura, Lorna, Molly), being '*in crisis'* was the most significant factor underlying their motivation and decision to learn mindfulness. This contrasted starkly with facilitator perceptions that mindfulness is *'best offered'* in 'more settled periods of time' (F 8). Gwen spoke about her sense of being in crisis and how this motivated her to learn mindfulness. She poignantly stated: *'I knew I wasn't going to survive unless I did something. I had to do something…Because I was falling to bits'.* The experience of 'crisis' for each of these caregivers was reported as having arrived at a point in which they felt their mental health and the sustainability of their ability to provide care to their significant other was at significant risk. Three of the caregivers (Gwen, Ava, Lorna) disclosed having felt suicidal at the point of deciding to learn mindfulness, with a sense of having exceeded all their normal coping resources because of the considerable challenges and losses associated with their role. Lorna explained, in detail, her crisis-point which led her to learn mindfulness:

> *I couldn't do anything. I couldn't cook, I was so depressed and so tired…I went to it* [learning mindfulness] *while I was in the real depths, you know, didn't know where to*

go. Really wanted to top myself… I just had enough in me to think you know, I need some help.

Caregivers, whilst conveying a strong sense of '*needing something to help them cope*', also expressed that making the decision to learn mindfulness was not without its tensions. Underpinning this tension was a pervasive sense of time in deficit and having to juggle too many other demands, as depicted in the previous chapter. Many participants talked about experiencing a struggle or fight between knowing that, '*I need this'* and '*I can't do this now'*, when making decisions about learning mindfulness. Laura explained, '*At the time I was very torn, half of me was "oh God, I can't do this right now". The other part of me was, this is what you need'.* However, many caregivers reported that if the person for whom they were caring was 'in crisis', this would have served as a barrier to accessing mindfulness whilst caregiving (Ava, Gwen, Laura, Lorna, Molly). For example, Gwen explained that it was not until her sister's health stabilised and she was no longer '*at death's door'* that she felt she was able to undertake mindfulness training.

When talking about engaging caregivers in mindfulness training, the facilitators in this study talked a lot about the importance of caregiver readiness: '*when they are ready*' (F5) and motivation, '*the degree that they want to be involved in learning mindfulness*' (F 9). One facilitator, who taught mindfulness to informal palliative caregivers alongside their significant other with cancer in a MBCT group context, explained how caregiver readiness and motivation were critical not only to caregiving engagement with mindfulness, but also the receipt of benefit. She explained that in her experience, caregivers who participated in mindfulness training by virtue of having to support care recipient attendance, did not derive as much benefit from this experience as caregivers motivated to engage in mindfulness for

their own benefit, or in her words: '*who were there in their own right doing their own practice, engaging as best they can with whatever their own needs are'* (F2). Another facilitator explained his observation of the importance of caregiver readiness and motivation to learn mindfulness as follows:

> *If someone is being pushed into learning mindfulness when they don't have any motivation, insight or desire to do it themselves, I think it's not necessarily helpful…If somebody sort of hears about mindfulness and says, "yeah seems like a good idea, I might try a little bit of it" and they are very 'luke-warm', then they will get some value but it won't necessarily be a lot of value. But if somebody is totally clear, totally ready and totally open to it, then they can travel quite a long way with it in a relatively short amount of time* (F 6).

Other examples also illustrated how a sense of readiness and motivation could enable caregivers to overcome great difficulties to access mindfulness programs if it was regarded as important to do so. One such example was Gwen, who travelled three hours return to access a group mindfulness program in a metropolitan area whilst caring for her sister. In another example, a facilitator shared a particularly poignant story about a caregiver who attended a mindfulness group despite significant experiences of loss and juggling multiple caregiving roles:

> *I remember she had a child, a husband with a brain injury and two children dying of this terrible disease. You'd look at her and think do you get to sleep at all, ever? Like what is she operating on? But here she was coming along every week* (F 4).

Whereas facilitators used the words 'motivation and readiness', the caregivers in this study used phrases such as '*people will know when it is the right time to learn mindfulness'*

and '*It's their journey. They've got to want to do it*' (Sarah). These words conveyed similar ideas to caregiver 'readiness' and motivation' but expressed a greater emphasis on empowerment; that caregivers can be self-reflective and self-determining in terms of when they are ready and able to engage with mindfulness training. Again, for five of the caregivers in this study, it was finding themselves at 'crisis point', that ultimately underpinned their motivation and readiness to learn mindfulness.

This first category 'engaging with mindfulness' provided a glimpse into how caregivers came to learn mindfulness and the factors underpinning their decision to do so. The following category unpacks a range of supporting factors that enabled caregivers to stay engaged with and receive benefit from learning mindfulness in the context of end-of-life caregiving.

6.3 Supporting Factors and Overcoming Challenges

The second conceptual category, 'The process of learning and using mindfulness in a disrupted world', describes the factors that support caregivers to overcome the challenges of learning mindfulness in the difficult caregiving landscape. Drawing on the myriad of challenges and the tension of limited time, detailed in Chapter 5, both caregivers and facilitators agreed that end-of-life caregiving was '*not an easy context to learn mindfulness*' (F 6). The following sections present two subcategories of findings identified as supporting caregivers to learn and gain benefit from mindfulness. These include: 'a flexible, person-centred approach' and 'skilled, supportive mindfulness facilitation'.

6.3.1 A Flexible, Person-centred Approach: 'A No-One-Size-Fits-All-Model'

In exploring the factors which enable end-of-life caregivers to learn mindfulness, the value of adopting a flexible and person-centred approach was strongly emphasised. A person-centred approach was spoken about as considering the unique needs, preferences and circumstances of individual caregivers in regard to how mindfulness is offered. A person-centred approach was clearly valued by participants, over a 'blanket' one size fits all type approach in the setting of end-of-life caregiving: *'Everyone is unique and individual…so you honour that. You meet the person where they're at and you go with that'* (F 10). For whilst caregivers share a common experience of caring for a significant other at the end of life, study participants emphasised that each person's experience of their caregiving world is unique to them. This person-centred and flexible approach was expressed as being applicable across two domains, format and timing, each of which are discussed below.

Format

The interviews revealed that mindfulness can be successfully learnt in different ways. Four caregivers in this study learnt mindfulness in a group-based format (Ava, Gwen, Jason and Sarah), three in a one-to-one session format (Bill, Laura and Lorna), with one caregiver (Molly) having learnt mindfulness by way of a smart phone mindfulness app. Four caregivers (Ava, Gwen, Sarah, Jason) learnt mindfulness in the context of a traditional intensive mindfulness program and four (Molly, Laura, Bill, Lorna) in an adapted, lower dose MBI. Similarly, facilitators reported having taught mindfulness to informal palliative caregivers using varied formats such as individual and group-based, delivery methods and in both intensive, as well as adapted formats. All caregivers and facilitators reported a wide range of benefits, irrespective of the MBI format. There was a strong view across

participants that *'there is not a one-size fits all model'* (F 4) for teaching mindfulness to informal palliative caregivers. In addition, the need to enable caregivers to be self-determining in choosing *'the right way for them'* (F 5) was highly valued by both caregivers and facilitators. For example, all participants spoke of strong variances in caregiver preference for either individual or group-based mindfulness formats. Four caregivers, (Ava, Laura, Lorna, Molly) spoke of their preference to learn mindfulness in individual one-to-one sessions. Their reasons included feeling less inclined to share and ask questions in a group setting, '*I'd rather one on one. In a group, you're less inclined to ask questions' (Lorna).* Two caregivers (Laura and Molly) did not want to interact with additional social contacts:

> '*I don't even see friends anymore. I am lucky to see my family anymore. I just don't have time and when I do, I'm too tired and don't want to make conversation (Laura).*

Gwen, however, described that learning mindfulness in a group-based format inspired a greater commitment to mindfulness practice and a sense of validating her own caregiving experience: *'It was validating in that some of their* [other caregivers in the group] *experiences were similar, if not the same as what I was going through'.*

Recognising and working with diverse preferences gave rise to the suggestion of '*having a menu'* (F 10) or '*a range of mindfulness practices*' (F 4) that can be matched to different individuals as opposed to always having to teach the contents of a full mindfulness course:

> *There are so many different ones* [mindfulness exercises] *that I'd use that I would adapt for the person - for the people that I'm working with. So that's what you do - as you get to know them* (F 3).

For example, a number of facilitators explained that, whilst they would ordinarily offer the intensive eight-week group-based formats, such as MBSR or MBCT, they have reconsidered this approach in light of the intensity and deficit of time, characteristic of end-of-life caregiving: '*People just aren't going to want to come to an 8-week course, are they?* (F 8). Caregivers and facilitators alike, expressed that teaching mindfulness in a way that '*is manageable'* (Molly) in end-of-life caregiving becomes the most important consideration: '*It's so intense, what is needed in that time, that it's really hard to ask people to do huge big things'* (F 7). Teaching '*smaller*' or '*more simple'* mindfulness elements and practices, from a more comprehensive MBI, in a one-to-one setting was proposed as one way of making mindfulness training 'more manageable' for end-of-life caregivers:

> *There's small, little things that we can actually pull out and definitely teach caregivers…You know, take a pause when you're doing something: informal mindfulness. When you're going to sleep and you're struggling, let's teach you to do a simple lying down body scan. Anything that helps ground them into their own body. Which one could do as an hour session here and there...so it's pulling out the little pieces of an MBSR program that people can remember. What are the small things? What are small moments that you can work with that make a difference?* (F 7).

Molly explained that receiving short, guided mindfulness instruction of 15- minute duration by way of a smart phone application, engendered a sense of it 'being possible' to undertake the learning of mindfulness in the context of caregiving:

> *It does feel manageable. I mean life is busy isn't it? There are so many demands on you and to take out 15 minutes, well if it was any longer than that, like if it was an hour or something like that, I would find that too much, yeah, at this stage*.

Laura also voiced having gained benefit from learning mindfulness by way of smaller practices that she could apply in the context of her daily life:

> *At the moment yeah, just a short quick something that I can do no matter whether I am sitting at the football watching my son or because my husband had a little bit of a tantrum - just something that I can do, something quick and easy that will calm me* (Laura).

In contrast, four caregivers were able to learn mindfulness in more intensive formats. Ava and Gwen took part in an intensive group-based mindfulness training, whilst Lorna and Bill participated in an intensive one-to-one training program. However, within these intensive models, allowances for the demands and uncertainty of caregiving were considered important factors to enable caregiver engagement with mindfulness. This included having opportunities to receive missed content, either personally (one-to-one) or by undertaking a 'catch up' class. Facilitators, likewise, emphasised their approach of relaxing expectations of caregivers having to attend all sessions, by '*allowing for those extra pressures that are put on people when caring for somebody who is ill*' (F 9).

Being more flexible in terms of 'formal mindfulness practice' requirements was valued as another aspect of making mindfulness training more manageable in end-of-life caregiving. For example, a number of caregivers (Ava, Bill, Gwen, Jason, Laura) expressed that it was often not possible to engage in the recommended daily formal practice requirements of 45 to 60 minutes: '*I would love to say I do it every night, but I don't*' (Ava). Whilst stating a concern that they were not '*practising as much as I should*' (Laura), caregivers appeared to resolve this tension by taking the position of '*doing what I can*' (Ava), within their current circumstances. Molly was the only caregiver who spoke of instituting

daily formal mindfulness practice sessions throughout caregiving. This regular practice, in Molly's view, was helped by the shorter sessions of fifteen-minutes and by embedding her practice early in her daily routine, '*I do my mindfulness at 7 o'clock or something like that, when the house is quiet*' (Molly).

Caregivers, overall, spoke of engaging in more 'informal mindfulness' or adopting a mindful approach in their activities of daily living, as opposed to engaging in formal mindfulness meditation practice. Facilitators also noted caregivers more readily practising 'informal mindfulness': '*being mindful when eating breakfast, being mindful when crossing the road, being mindful when walking in the park and hearing the birds and smelling the flowers' (F 6).* All caregivers reported benefit from mindfulness, irrespective of how much or how little formal practice they engaged in.

The use of technology was experienced as another avenue for supporting greater flexibility or making mindfulness 'more manageable' in the context of end-of-life caregiving. Three facilitators (1, 4, 8) spoke of delivering mindfulness training by phone, with good effect. This was seen to overcome barriers faced by caregivers in terms of accessing face-to-face MBI in a fixed time and place. One facilitator described teaching an adapted MiCBT training by weekly telephone calls of an hour's duration to a rural caregiver, '*She was rural. I couldn't possibly get to her. It was just one person. So, we tried it over the phone and that seemed to work just as well'* (F 1).

Another facilitator spoke of delivering mindfulness training via smart phone applications (apps), in instances where mindfulness training was inaccessible to caregivers by any other means. Molly for example, relayed a very positive experience of learning mindfulness through a mobile phone application. She noted it was not viable for her to

access mindfulness in a group setting and valued the portability and flexibility of the mobile app and how it taught her mindfulness in the comfort and privacy of her own home:

> *I don't have to go anywhere. Because I do go places. I have to go to meetings and go to school and go shopping, go here and go there. It's nice to have something you don't have to go out for. I like being at home* (Molly).

A number of participants (F 1, 4, 8, Gwen, Laura, Ava), whilst not having trialled mindfulness-based apps, expressed the view however that this mode of delivery would not allow for a supportive relationship with a skilled mindfulness facilitator nor the opportunity to discuss their practice:

> *I'm really not into apps or that sort of thing but I do wonder if there was a specific app and it would need to be called something like 'stress relief for carers' or something. Maybe that would be a way in which people could just take it in, but I think it's a very hard thing to learn without a teacher too* (F 8).

Timing

Just as the caregivers in this study had learnt mindfulness in different formats, findings revealed that they also learnt mindfulness at different time points in relation to their caregiving experience. Six carers had learnt mindfulness whilst actively caring for their family member at the end of life (Ava, Bill, Gwen, Laura, Lorna, Molly). Two had learnt mindfulness many years prior to caregiving (Jason, Sarah). There were quite diverse views regarding when to offer mindfulness training in end-of-life caregiving, the strongest contrast being between the views of caregivers and facilitators. For example, several facilitators (F1, 2, 3,4, 6, 8, 9,11), but only one caregiver (Sarah) regarded learning mindfulness in the early

stages of caregiving, to be '*easier*' and '*much better'* as opposed to the more intense and unsettled periods of caregiving:

> *It's good to learn to sail when the winds aren't blowing too much... you could still practise when it's stormy but it's going to be harder to do* (Sarah).

Learning mindfulness early in caregiving was perceived to equip caregivers with an established resource that could be more easily accessed in the face of escalating difficulties:

> *I think if you've had contact with it, a practice and all that learning has already happened, then yeah I think it's in you, isn't it? Then it's able to be drawn on, but to find it while you're in that threat stage, I think it's really tricky* (F 8).

Bereavement was regarded as another conducive time by many facilitators (1, 2, 5, 8, 10, 12) for caregivers to learn mindfulness, as opposed to learning mindfulness whilst actively caregiving, due to caregivers having more time and space to learn and cultivate the skills of mindfulness:

> *Quite often when a person's past the situation, a lot of the weight is gone. They have more time. They have more space and they can be more reflective…they've got time to practise and the time to do it well. Whereas a lot of people who are in a caring situation find it's very hard to find the time* (F 1).

Bereavement was particularly advocated by facilitators as the 'better time' for learning mindfulness in more intensive formats, such as group based MBSR or MBCT:

> *I actually think that it's quite hard to offer it* [MBSR course] *to people at that time* [during caregiving]. *That they haven't got the time. They haven't got the resources. They haven't got the spaciousness to develop a practice, I don't think* (F 8).

However, as touched upon in the earlier sub-category of the catalyst of crisis, the caregivers in this study strongly cautioned against the assumption that situations need to be calm and settled in order for caregivers to learn mindfulness. For example, Lorna explained that she learnt mindfulness when things were at their most difficult, dark and tumultuous. She therefore, advanced the idea that 'anytime' could be the 'right time':

> *Lorna: It's always the right time. It wouldn't matter what you were doing. Because I know from being in the depths. Well it was for me. Anytime would have been the right time.*
>
> *LJ: I thought maybe it's going to be too hard when you're that low?*
>
> *Lorna: No, well, it wasn't. No, encourage it as much as you can.*

Rather than referencing external events and challenges to determine what constitutes the most conducive time for caregivers to learn mindfulness, all eight caregivers interviewed, held the view that the best time for caregivers to learn mindfulness '*would depend on the person'* (Sarah) and their particular circumstances at the time:

> *I think depending on where you are on that path* [caregiving] *as to - and what's happening in the rest of your life as to when would be the best place along that path for you to get that* (Laura).

Throughout participants' accounts of when and how to deliver mindfulness-based approaches to informal palliative caregivers, a strong view emerged that learning mindfulness is a process that evolves with practice over time, extending well beyond the time frame of mindfulness courses, typically of eight weeks duration, '*It's* [mindfulness] *a lifelong course really. It's just squashed into eight weeks'* (F 1). This was seen to afford the opportunity for caregivers to learn mindfulness at many different time points along the

caring continuum, even if they began in only small ways, with the possibility of being able to '*come back to it'* (F 5) or engage in more intensive learning, when circumstances permitted:

> *Even though they're in a very difficult period of their life and probably the most intense period of their life - they can still gain from it, even though they can't get it fully…Then they might come back and say, can we do it again now that that part of their life has finished* (F 1).

The value of adopting a flexible and person-centred approach to the format and timing of mindfulness training, over a prescriptive and rigid one, was identified as the first supportive factor enabling caregivers to learn and gain benefit from mindfulness. The prevailing issue for caregivers and facilitators alike, was to offer a range of approaches and facilitate caregivers to be self-determining in terms of when and how to learn mindfulness according to their own needs, preferences and circumstances.

6.3.2 Skilled and Supportive Facilitation

Another critical factor enabling end-of-life caregivers to learn and gain benefit from mindfulness, spoken about by both caregivers and facilitators, was skilled and supportive mindfulness facilitation. This factor was also experienced as fundamentally important in mitigating potential negative effects of learning mindfulness in caregiving or indeed in any other setting. Whilst valuing a flexible approach to the provision of mindfulness-based approaches in end-of-life caregiving, it was strongly emphasised that they should be taught by facilitators skilled and experienced in mindfulness and who embody what it is they are teaching. This was regarded as one way of not losing the essence of mindfulness when teaching components of what are ordinarily holistic and comprehensive programs, like MBSR and MBCT.

The finding of 'skilled and supportive mindfulness facilitation' is explored in this section through the following sub categories: 1) facilitating safe and supported learning and 2) mindfulness practitioner training, practice and embodiment.

The skilfulness of facilitators establishing and holding a '*safe and supported space'* in which caregivers felt comfortable to learn mindfulness amidst a disrupted world of caregiving, was emphasised as critical. This was underpinned by a view, especially for facilitators, that caregivers were in a more uncertain and vulnerable space than other clientele in non-palliative contexts: '*They're in essentially an unsafe situation…I think the skill of the facilitator is, I'd probably say 'heightened', in this case'* (F 9). Maintaining this safe learning environment was perceived critical to both helping caregivers remain engaged with and to receive benefit from mindfulness. A facilitator teaching mindfulness to bereaved caregivers suggested that establishing a safe space included maintaining a climate of non-judgement. She explained how this can be a very empowering experience for caregivers, who often judge themselves very harshly or are judged critically by others regarding how they are navigating their grief experience: '*When I explain, well you're not going to get any judgement from me, they are really surprised and relieved'* (F 10). Caregivers similarly talked about being able to '*trust*', '*feel safe with'*, '*supported*' and '*not judged by'* their mindfulness facilitators, indicating that this aided them to sustain their engagement with mindfulness and to face the emerging challenges in their practice and life more broadly. Laura explained how, prior to learning mindfulness, she would rarely talk about the emotional things in her life. However, in sessions with her mindfulness facilitator, she felt safe to share what was happening: '*I let my emotions come when I am there, when I'm having that meeting it's talking about everything that's going on'.*

Even for Molly, who used a mindfulness-based app, the experience of feeling 'connected' with a mindfulness facilitator remained important. Surprisingly, in a format that could feel impersonal and removed, Molly spoke of experiencing a supported connection, helped by the constancy of one mindfulness guide [Adam] across the suite of guided mindfulness audio recordings:

> *I know that it's always going to be Adam…Occasionally you will get an actual video …it makes it more - personalises it, doesn't it? Now I know who is talking to me, it is not just a voice out of the ether; there is an actual person there.*

Having been 'supported', 'guided' or 'coached' to learn mindfulness, was highly valued by the caregivers in this study, with a view that it would have been too difficult to learn by themselves in such a challenging context as end-of-life caregiving, '*I don't think I would have been able to do it on my own'* (Laura). Caregivers particularly valued the support to build their confidence in their mindfulness practice and being able to ask questions: '*You need someone to answer your questions about what you're experiencing and what's normal and what you can expect'* (Sarah)*: 'you benefit from that coaching'* (Gwen). This interactional component was not an option for Molly in her learning mindfulness from a smart phone app. However, for Molly the dyadic component was less important than the flexibility and portability of being able to learn mindfulness at home, due to her escalating caregiving demands. Having a skilled and experienced mindfulness teacher to answer questions about and offer caregivers a chance to 'debrief' their experiences, particularly the challenges they may face in applying mindfulness in everyday life, was strongly emphasised by facilitators:

> *It is very helpful if they* [caregivers] *have someone they can talk to about what is happening. "This is the reaction I had to that, and this is the effect that this had". So, if they are able to explore and debrief they will deepen their learning. So, having ongoing support in learning and applying mindfulness, I think is very important* (F 6).

Clearly, the need for caregivers to feel safe and supported to learn mindfulness, within such an intense and uncertain experience as end-of-life caregiving was considered critical by both the caregivers and the facilitators in this study. Furthermore, establishing and maintaining this safe learning environment was perceived to be an essential skill and responsibility of mindfulness facilitators.

The facilitators in this study further outlined a range of specific skills and experiences deemed important to enabling caregivers to learn and gain benefit from mindfulness in end-of-life caregiving. These included facilitators having undertaken mindfulness training, having an established self-practice and embodying or modelling a mindful approach themselves. Being their field of practice, it was not surprising that facilitators in this study spoke more about this than caregiver participants.

From the experience of the facilitators in this study, skilled and effective mindfulness facilitation was strongly perceived to be anchored in having undergone an intensive mindfulness course, '*having done it yourself first*' (F 4. 8, 9). However, facilitators emphasised training was not sufficient in itself to consolidate a full understanding of mindfulness and talked about the importance of facilitators having both training and a lived experience of mindfulness practice:

I think whoever's providing mindfulness, whether it might be an individual providing it one-on-one or a facilitator doing it to a group, they need to be engaging in mindfulness practice themselves. I think it's a false sort of teaching or skill to be giving if you're not utilising it yourself (F 12).

Skilled facilitation was also seen by facilitators in this study to involve the embodying and modelling of mindfulness in their work with caregivers: '*The most important part of mindfulness is not in the direct teaching of it, but in the modelling of it or the 'being' of it'* (F 6). There was a universal concern among the facilitators in this study, that in the absence of this embodied and lived experience of mindfulness and the intimate encounter it provides with the evolving process and challenges of maintaining a mindfulness practice, caregiver receipt of value and benefit would be significantly compromised:

We're not going to have the outcomes that we want if organisations expect to be able to send their staff out to do an eight-week training course in mindfulness. "Okay, you've got mindfulness, now you can teach your clients". It's exceptionally rarely the case…one eight-week course just doesn't cut it (F 4).

6.4 Considering the Potential for Adverse Effects

'Considering the potential for adverse effects' constitutes the final conceptual category relating to the 'process of learning mindfulness in a disrupted world'- the second overarching process in this study. It distils both caregiver and facilitator experience and perceptions of the potential for adverse effects from learning mindfulness in end-of-life caregiving.

In exploring the existence of negative or adverse effects of learning mindfulness, none of the caregivers interviewed in this study reported experiencing adverse or harmful

effects themselves, nor could they identify any potential negative outcomes as a result of learning mindfulness within the caregiving landscape. Gwen and Lorna experienced mindfulness training as *'a gentle thing'* and held a strong view that as a result *'it does no harm'* (Lorna). Laura carefully considered her experience of mindfulness as a caregiver and what she knew of others' experiences and stated: '*I can only say good things about it and I can't think of any way that it could possibly be negative for anybody'.* Further, caregivers did not perceive any potential for adverse effects for other caregivers if they were wanting to learn mindfulness. However, as discussed in the previous section, essential to this experience were supporting factors such as having had a skilled facilitator to teach them in a safe and supported way. Considering that caregivers reported being well supported, (or 'well-guided' in Molly's case), had this study recruited caregivers without such support, or if they weren't ready or wanting to engage in learning mindfulness, negative outcomes may have been identified.

When asked to reflect on potential adverse effects from learning mindfulness in end-of-life caregiving, all facilitators acknowledged needing to stop and think more deeply before addressing the issue: '*Good question. I'm not going to deny that there possibly isn't. Nothing's just springing to mind at the moment, I suppose'* (F 12). One facilitator (F8) expressed surprise at the question, stating she didn't perceive any risks in offering MBIs to caregivers or any other population, believing people are resilient: '*I really do believe people can work with stuff*' (F 8). With further prompting, facilitators outlined a number of potential adverse mental health effects, drawing on their experience of offering MBI across different populations, not just to caregivers. Primarily, caregivers with existing mental health issues were regarded as more susceptible to adverse mental health consequences from learning mindfulness: '*it depends on people's mental stability, to a degree…so you have*

to take care around that' (F 5). For example, careful assessment of caregivers' individual needs and issues and modifying mindfulness practices in response to safeguard mental health was emphasised (F 2, 7, 9, 10, 5, 4, 8). One facilitator reflected on her own process of assessing and modifying mindfulness practices in response to the protective coping strategies adopted by a caregiver with anxiety:

> *As soon as we got into open awareness practice, that was just a no go for her. That just opened up the floodgates of all manner of things and the thing that she found so workable for her was just coming back to an object like the breath or sound, so we just had a little side track of practice for her. That worked well* (F 8).

This mirrors the earlier finding of valuing a person-centred approach to the timing and format of delivering mindfulness-based approaches in end-of-life caregiving. Facilitators were able to outline several potential negative effects for more vulnerable caregivers, however, they also strongly communicated that these could be mitigated by skilled and experienced mindfulness facilitation:

> *It* [mindfulness] *needs to be really well facilitated, because if it is poorly taught then it can have some, you know, some uncomfortable outcomes. It's not because the mindfulness process doesn't work; it's just because the person's not learning it properly…So I think a person needs to be taken gently through the process with a sensitive and experienced teacher* (F 6).

For example, a number of facilitators (6, 5, 8, 4, 12) identified, from their experience with other populations, that there was potential for some caregivers to experience a sense of failure if they could not practice, or integrate mindfulness into their lives, according to their expectations: '*It's easy to give someone a skill or an approach and for them to struggle to*

use it because they haven't integrated it as a skill yet and then criticise themselves more' (F 4). However, the presence of skilled mindfulness facilitation, which involves supportive mechanisms such as *'following up'* (F 3) and '*staying in touch'* (F 8) with caregivers to ensure they feel supported and are not placing unrealistic expectations on themselves, was perceived to be protective against this interpretation of failure.

The surfacing of past traumatic experience was noted by facilitators *(*10,2,7,1,3*)* as another potential adverse effect of learning and practising mindfulness in any context, not just caregiving: '*If there's a pre-existing area of trauma, whether it be psychological, or whether it be in the body…There can be issues there'* (F 9). Facilitators again emphasised the importance of facilitators to be skilled in responding to trauma activation: '*You need to know how to do that work* [trauma work] (F 3). Other facilitators (F 1,5,8) expressed that, whilst mindfulness had the potential to surface trauma, paradoxically it could also provide a way to work with and transform their relationship with traumatic experiences: *'it* [mindfulness] *gives a person more ability and more strategies to be able to cope with a heavy situation'* (F 1).

Another potential adverse effect of mindfulness, or at least certain practices, mentioned by three facilitators (4, 9, 10), was the triggering of altered states of consciousness[3]. However, most facilitators regarded the potential for altered states of consciousness in the context of end-of-life caregiving to be less likely than in other contexts. This was due to the use of adapted, less intensive mindfulness practices in end-of-life caregiving: *'Because they do not go deep enough they are not able to reach those high*

[3]Altered states of consciousness in this context refers to the potential for a loss of contact with reality such as may be seen in a suicidal crisis, a psychotic episode or trauma response of dissociation in those experiencing particular severe mental disorders and practising mindfulness.

qualities of mindfulness that can give you altered state of consciousness' (F 11).

One facilitator noted that another perceived negative mental health outcome of learning mindfulness was a fuller awareness of the difficulty of their situation and a subsequent increase in depression. He recounted one caregiver's experience as follows:

> *He said he really got a lot out of it* [learning mindfulness]. *But towards the end that it made him more depressed because he found that what it did was open his eyes to the situation that he was in ... it's an interesting concept that sometimes our ignorance is better than knowing the full truth* (F 1).

Contrasting perspectives did not frame the experience of increased depression as an adverse effect. Instead encountering and recognising the full impact of their experience, however difficult, was seen by some facilitators as a critical aspect of learning mindfulness, providing caregivers with an opportunity to transform how they related to difficult issues in their life (F 8, 10).

> *That's what mindfulness is for. Actually it's going to be really challenging and these things are going to come up and they're good that they come up because then they learn how to process them better... they've got an opportunity to become aware and have a relationship with and transform it, but if they and we get stuck in protecting them from feeling the problem, then I think there's no movement. There's no change, that stuck-ness* (F 8).

These findings demonstrate that all the participants interviewed in this study found it difficult to identify adverse effects or problems with caregivers learning and using a mindfulness-based approach in the setting of end-of-life caregiving. No caregivers interviewed in this study, reported experiencing adverse effects themselves from learning

mindfulness or anticipated there would be for others in their situation. Whilst facilitators struggled to identify any concrete examples of caregivers having experienced negative impacts from learning and practising mindfulness, they outlined a small number of potential adverse effects for caregivers with existing mental health issues. However, skilled and experienced mindfulness facilitation was perceived to mitigate these potential adverse effects from learning mindfulness in caregiving.

6.5 Chapter Summary

This chapter has presented the second overarching process identified in this study: 'The process of Learning and Using Mindfulness in a Disrupted World'. It explained how caregivers come to learn mindfulness, what this can look like, the challenges involved and the factors that support caregivers to engage with and receive benefit from mindfulness amidst the difficult landscape of end-of-life caregiving.

The following chapter explores what the experience of learning and using a mindfulness-based approach offers in the context of end-of-life caregiving and what this means to caregivers and the person for whom they are caring. In similar fashion to this chapter, it does so by deeply contextualising the experience and benefits of learning mindfulness within the context and characteristics of 'a world disrupted', portrayed vividly in the first results chapter in this thesis.

CHAPTER 7

GAINING IN A LANDSCAPE OF LOSS: THE VALUE AND BENEFIT OF MINDFULNESS IN END-OF-LIFE CAREGIVING

7.1 Chapter Introduction

This is the last of three findings chapters. Chapter Five, detailed the context and characteristics of the end-of-life caregiving landscape, largely described by the caregivers in this study. Chapter Six integrated the views of both caregivers and mindfulness facilitators to describe the process of learning and using a mindfulness-based approach in this landscape, specifically how and why caregivers engaged with mindfulness, the enabling factors and challenges encountered. This chapter provides a rich, integrated understanding of the value and benefits of learning and using mindfulness in end-of-life caregiving, as experienced by both mindfulness facilitators and caregivers themselves.

This chapter is organised around five key categories of benefit derived from learning and using mindfulness in end-of-life caregiving. It is important to note that each of these benefits were described and contextualised in diverse and complex ways. However, there was a high level of interconnectivity amongst these categories and the processes underpinning them. These categories include: 1) repositioning self; 2) engaging with the full range of experiences; 3) connecting with and caring for self; 4) strengthening relationships and 5) realising a resourceful and empowered self. Each of these findings categories will be presented.

7.2 Repositioning Self

This section explores the finding of 'repositioning self' as the first conceptual category relating to the benefit of learning mindfulness in end-of-life caregiving. It details a positive shift in the way caregivers come to relate to their caregiving and broader life experiences and how they assigned clear significance to this process of repositioning. It is comprised of two interrelated processes, presented here as the sub categories of 'stepping back from enmeshment' and 'stepping into a more grounded space'. The category of 'repositioning self', whilst spoken about as a benefit in and of itself, was also regarded to be a 'meta process' that enabled a range of other benefits that will be outlined following this section.

7.2.1 Stepping back from Enmeshment

Permeating all interviews, was the view that learning mindfulness supported caregivers to 'reposition' themselves in relation to their thoughts, their feelings and the events occurring around them. Specifically, participants richly described that mindfulness had enabled a shift or movement away from being deeply enmeshed in or fused with their experience, akin to taking a step back to adopt a position of observer of their experience, as opposed to being entangled in it. Descriptors such as *'stepping back'*, '*pulls me back from'*, '*brings you back into the middle' and 'not be so caught up in'* conveyed the repositioning that caregivers described experiencing because of learning mindfulness.

Molly described mindfulness as facilitating a new sense of distance between herself and her thoughts, which she saw to be beneficial: '*it distances me a bit and you can remain calm and not get involved and that's good'*. When asked what 'getting involved' had looked like in the past, Molly explained being agitated by and unable to escape her thoughts, which

were heavily focused and enmeshed in concerns about 'coping' with caregiving. Facilitators also spoke of observing and recognising similar benefits amongst caregivers:

> *They* [caregivers] *step back and notice that their mind is running through all those different thoughts and ideas and solutions to the problems they're facing, but to not be so caught up right in amongst it all* (F 12).

Facilitators used phrases such as being '*less tangled in'*, '*less overwhelmed by*', '*less subject to'*, '*less defined*' by thoughts, feelings and experiences to describe the benefits they observed amongst caregivers who were learning or had learnt mindfulness. Facilitators relayed that mindfulness assisted caregivers to gain a new sense of themselves as being separate to or larger than the experiences they confronted as opposed to feeling fused with, paralysed by, or totalised by them. Both caregivers and facilitators, however, strongly emphasised that this was not about disengagement or alienation from the caregiver experience, but involved a convergence of both acceptance as well as an adoption of a bigger, decentred perspective:

> *When you practise mindfulness of your condition, your pain is not you, your thoughts are not you. That perspective taking, really is compelling … At the same time, it's a deep recognition of acceptance that I am in this situation with this pain, with these thoughts. It's both. It's a polarity, isn't it, a real recognition of this is mine to look after. I need to relate to this* (F 8).

In further discussing the benefits of 'stepping back from enmeshment', caregivers and facilitators both spoke of mindfulness enabling a positive repositioning in terms of time or an ability to step back from being preoccupied with recent difficult events or concerns for the future, to reclaim the present moment. For example, most caregivers described their

lives prior to learning mindfulness as characterised by being either in 'past time', through ruminating on and revisiting past experiences associated with caregiving or being swept into 'future time', anticipating and projecting fears about what lay ahead for them. Prior to learning mindfulness this preoccupation with past and future time was described as serving to enmesh them in their fears, anxiety and stress: '*I felt like I was always anticipating or reflecting or planning or scheduling and looking back and analysing'* (Laura).

One facilitator explained his observations of how living in 'non-present time' played out for caregivers in their landscape and how mindfulness served to offer a way of countering this:

> *If a person is anticipating stress and difficulty in the future and lives that in their mind in anticipation, thousands of times before those events even happen then that multiplies the stress enormously. Learning to be present means just learning to deal with each moment, allowing that moment to be what it is and when its passed, its passed and not to live future events before they've even happened* (F 6).

Caregivers themselves also spoke of learning to be in the present moment, to step back from or avoid becoming too enmeshed in their feelings and ruminations. Ava and Gwen both used the same phrase, '*brings me back to the present moment'*, to describe their sense of how mindfulness had helped them in their caregiving journey. Gwen provided detailed insight into what it was like for her to step back into the present moment as opposed to 'taking off' in fearful future thoughts:

> *It* [mindfulness] *helped when things were really bad from not getting ahead of myself into the future with respect to, okay if this doesn't go the way we want, and she dies, what do I do without my sister? How do I take care of all her belongings? Her paperwork? The whole estate thing?... Instead of my mind exploring or going down*

those pathways - which were not nice pathways - just pulling back to the moment. She's alive, she's breathing, she's getting help.

While participants acknowledged that 'coming back' from future orientated thinking into the present was a benefit of mindfulness, facilitators especially perceived that this was a challenging practice for some caregivers, because of the very nature of their caregiving landscape:

> *For them not to scan the future and come back to the present moment here and now…not scanning to see how my partner is going, I'm not scanning for danger. I'm not scanning for disaster. That can feel counterintuitive for some people* (F 9).

However, the perceived benefit for caregivers to acquire a sense of distance from the *'anxiety and fear of the future'* (F 7), even for brief moments, was regarded to be worth the adjustment and to experience '*what the gift of mindfulness is*' (F 7).

The acquired ability of caregivers to 'reposition' themselves in relation to their experiences, through a process of stepping back from being enmeshed in their thoughts, feelings and events occurring around them, was clearly a valued benefit of mindfulness from the experience of the participants in this study.

7.2.2 Stepping into a more Grounded Space

The subcategory of 'stepping into a more grounded space' describes an additional process underpinning how mindfulness supports caregivers to reposition themselves from enmeshment and overwhelm. The participants in this study richly described what it was like to 'step into' a new grounded space offered by mindfulness, drawing deliberate and sharp contrasts with the more fraught, busy and overwhelmed space commonly experienced in

caregiving. The following section details three characteristics of the new grounded space afforded by mindfulness, as expressed by both facilitators and caregivers. These include a place of calm and rest, being more aware and occupying brief but important moments of respite. The experience of stepping into this new repositioned space opened up by mindfulness was described in a variety of positive ways by caregivers including '*calm'* (Laura), '*more peaceful'*, (Bill, Lorna) *'more centred'*, (Laura) and *'more balanced'* (Gwen) and as a place of stillness or '*a little place to rest in'* (Bill). All these descriptions contrasted vividly with the challenges of the caregiver role as outlined in Chapter 5, including the continual juggling of multiple demands and responsibilities. For Laura, mindfulness opened a space where *'everything can stop for a little while'.* These spaces were highly valued as the only moments she had to rest and recharge within the demands of caregiving, parenting and full-time work. Laura further described how in those mindful moments, not only does the juggling stop, but that the balls disappear altogether *'they are not even there'.* When asked to explain what was there in those moments instead, her reply was, '*Me, just me*'.

Mindfulness was also experienced as offering a '*clearer space'* or one that enabled caregivers to gain '*a sharper focus'* or '*increased awareness'* of their unfolding experiences. This clearer space was juxtaposed against the more common description and experience of navigating end-of-life caregiving as '*being clouded'* or '*in a blur',* with little space to reflect on what is happening. Molly explained the sharpened awareness she gained from learning mindfulness:

> *From time to time you sort of notice where you are and what you are doing and where your mind is and how you are feeling, and all those things. Whereas when*

before um, the sort of day passes in a bit of a blur really, doesn't it? You're sort of going from one thing to the next and without much awareness, is the word.

Participants talked about being clearer or having greater awareness across the three key domains of thoughts, emotions and the reality of their situation. For example, mindfulness was perceived as particularly helpful in enabling caregivers to gain insight into how '*busy*, '*racing*' and '*distracted'* their minds tend to be, particularly in planning for and managing care. One facilitator argued that through learning mindfulness, caregivers come to see:

…how they get very caught up in trying to determine what is going on, what this symptom means, what needs to be done to manage it. So how they get very trapped inside their mind trying to figure all that out and provide the best care (F 12).

For some of the caregivers in this study, gaining insight into the constant activity of their minds subsequently provided them with a way to 'quieten' their thoughts. For Laura, one of the most valued benefits of learning mindfulness was the moments it provided for her to seek respite from the barrage of thoughts that occupied most of her waking moments: '*it's a way of switching off my head'* (Laura). Facilitators also expressed that in gaining knowledge and control over their thoughts, mindfulness enabled caregivers to establish:

A new relationship with their mind…there is a sense that I have a choice. I can make the decisions here and not everything is dictated by what my mind is telling me (F 12).

The opportunity for caregivers to quieten a constantly restless mind, however, whilst valued, also evoked a tension at times. Laura stated that mindfulness enabled a realisation

that her busy mind with its ruminating thoughts around work-related problems provided a strategy of distraction, so she didn't have to think about what was happening with her husband and his illness. She explained, *'I wondered if I'm doing that as a distraction, because I'm not then thinking about my situation at home with my partner?'.*

In addition to gaining a clearer perspective on their thoughts, both caregivers and facilitators talked about how caregivers gained an increased awareness of their own emotional states in this repositioned space. Sarah explained that mindfulness enabled her to identify and acknowledge moments in which she was struggling with her emotions, '*ahha that's my struggle',* which appeared to offer her a sense of agency in relation to her feelings and how she chose to respond them:

> *To be able to see that I was struggling with my emotions... Like even in that moment, even though I don't feel like I can change it, I can just go ah-ha, I'm struggling with this* [laughs]*. There's the sadness and now I'm feeling anxious about the sadness and if I get stressed about the anxiousness that's not going to help.*

Being more aware of emotions was also regarded by facilitators to help caregivers exercise more considered choice in '*how they chose to respond or act'* (F 8) when faced with the unrelenting adversities encountered in the caregiving landscape. One facilitator (F 2) relayed how they had observed mindfulness to help a female caregiver better manage her anger and in doing so, preserve important relationships in her life:

> *Mindfulness helped her not be angry. Well she was still angry, but she did not let the anger spill over. All the stuff around choices* (F 2).

Mindfulness was also perceived to support greater awareness amongst caregivers of how emotions are not fixed states, that they '*change' and lift'* (F 10) and that it was possible for them to be with or 'ride the tide of emotions', as opposed to shutting them down, for fear of being capsized by them:

> *I think the mindfulness, too, holds people - they understand things go up and down, but they too go up and down. They don't stay - the pain is really severe at times and then it eases and then it comes back and then they learn how to roll with that more* (F 5).

The repositioned space, afforded by mindfulness, was also perceived to support caregivers to be able to see more clearly and better consolidate the reality of their situation in a way that didn't destabilise or overwhelm them and which enabled them to make more considered choices in their lives, which included '*learning to see things as they are and then make a decision about what if anything needs to happen'* (F 4). Sarah gave a powerful example of how being more aware of the moment and what she valued, helped guide an important interaction with her mother a few days before she died. Sarah described how mindfulness supported an awareness that her mother's time was limited and to 'tune in' to what was important for her as a daughter. She expressed that mindfulness enabled her:

> …*to be in the moment and be conscious enough to think about what I wanted to do and say and to put the side rail down* [emotional, teary, laugh] – *because actually I wanted to get in close and say what I wanted to say* (Sarah).

Sarah explained that had she not been able to occupy that more aware, '*clearer seeing*' space she attributed to learning mindfulness, that significant moment would have been lost to both her and her mother. However, participants also emphasised that taking a 'step back'

from being enmeshed in their experience into a clearer, more grounded space was not a permanent relocation but rather a process of '*coming in and out of'* or oscillating between the mindful and more chaotic moments of caregiving.

Both caregivers and facilitators spoke of one further characteristic of the new repositioned space afforded by mindfulness, represented here as the concept of 'brief but important moments of respite'. Participants indicated movement into the more grounded, present moment space was frequently brief, '*only for a while'* (Molly, Laura, Lorna) or '*in little bits and pieces*'(Bill). However, these moments of untangling themselves from their experience and becoming more centred were extremely valued by caregivers. Jason acknowledged that very brief moments could help ground him in the face of difficult experiences: '*I got very into the present moment. It was only for a minute, maybe. But it definitely - I noticed the change in me'.* These brief mindful moments were conveyed as providing a welcomed respite from the grief and pain, characteristic of end-of-life caregiving:

> Y*ou can't take the pain and you can't take the awfulness away. But having moments, even if it's just small moments of 30 second here, 30 seconds there… is really important* (F 10).

The view that significant benefits could come from small shifts in the way in which caregivers related to their experiences was communicated strongly by participants, as was the potential of '*brief mindful moments'* to afford an enduring benefit by enhancing a sense of personal agency. One facilitator described a common caregiver response to the repositioning of self in relation to experience as follows:

> *The very small tiny shifts I can make matter. They are of value…big things come out of tiny shifts and changes…I felt powerless in relationship to this thing* [end-of-life caregiving]*, but I can make tiny little shifts in how I live during the days and that makes a big difference to how I feel in my life* (F 8).

This idea that mindfulness can transform a day, an hour or a minute into more manageable moments, is a profound finding, particularly in the context of such an intensive, time limited landscape as end-of-life caregiving.

'Repositioning self', as the first category of benefit, demonstrated that mindfulness offers brief, but important moments of stepping back from enmeshment and overwhelm to occupy a more grounded, present moment space. The value of this space, as the only space of calm and rest amidst the difficult experiences and multiple demands of caregiving, was emphasised by caregivers and facilitators alike. The repositioned spaced was also regarded to afford greater caregiver insight into their thoughts and feelings and the reality of their situation, which subsequently aided decision making and actions that accorded with what they valued.

7.3 Engaging with the Full Range of Experience

The second category of benefit, relating to learning mindfulness in end-of-life caregiving, is 'Engaging with the full range of experience'. This category presents how caregivers develop a more effective and balanced way of engaging with difficult experience as a result of learning mindfulness.

7.3.1 Engaging with, as Opposed to Avoiding Difficult Experience

Prior to learning mindfulness, caregivers spoke of commonly adopting an approach of 'seeking to avoid' or 'distract' for the more difficult aspects of their caregiving experience This avoidance stance was explained by facilitators, in their experience, as being a natural reaction amongst caregivers, who feared that openly engaging with difficulty and distress within their lives would likely cause more suffering and undermine their capacity to cope. Facilitators spoke about the impact of avoiding difficult experiences on caregivers:

> *When we are confronted with something that is uncomfortable, we want to ignore it or push it away or pretend it's not there, but that doesn't really make it go away or alleviate the suffering that is there. It just puts it off and often compounds it* (F 6).

One facilitator shared how these commonly held assumptions have manifested in many caregivers with whom she had worked. She explained that some caregivers had adopted a binary approach to their experience, which was not always helpful in accepting the reality of their situation: *'You have families that only look at the positive, that refuse to look at the difficulties'* (F 7).

Mindfulness was perceived to offer caregivers a more adaptive approach to working with end of life challenges: one that invited acknowledgement and engagement with the full range of experiences, including those perceived as difficult and distressing. This approach was variably described by caregivers as learning '*to face',* (Laura)*'* or '*to be with*', (Ava) difficult experiences and by facilitators as learning '*to tolerate'*, '*open up to'* and '*sit with'* both the good and bad in experience or '*the ability to be with the full catastrophe'* (F 8). Other participants used descriptions such as '*not avoiding'* or '*not distracting'* from the difficult experiences they were encountering in caregiving. For example, Lorna spoke of how

mindfulness enabled her to acknowledge and accept when she was feeling depressed, as opposed to avoiding it: *'Now I can tell if I'm going to feel a bit low.…don't try and dismiss it. You accept it*'. She explained that prior to learning mindfulness in caregiving, she employed the strategy of distraction or avoidance which she found to be largely unhelpful, '*That's the worst thing you can do'.* Lorna also powerfully drew a strong contrast between mindfulness as '*a more gentle and effective approach'* and her experience of a life-time of invasive medical intervention which sought to remove her depressive thoughts and feelings:

> *I had years of psychiatrists stuffing things down my neck. I had this thing, you know, electrical things* [electric shock therapy] *masses of it too...six weeks of it at a time, twice a day, every second day.*

Lorna strongly felt that by practising mindfulness, she gained an effective way to manage her difficult emotions through '*accepting and letting go',* which she described as *'so releasing'* and *'far more humane'* than her previous therapies.

Whilst the term 'acceptance' was commonly used by caregivers to describe this new way of engaging with difficult experience, it was regarded by two facilitators (F 12, 10), as a difficult construct within the palliative care and bereavement context. This was largely because of its tension with the more predominant paradigm or concept of 'fighting' within palliative and cancer care. Facilitators had observed patients and families to commonly adopt the stance of 'fighting the disease', 'fighting for life' and 'fighting against unwanted situations and feelings'. Facilitators further explained that, in their experience, many caregivers take the view that to do otherwise, to accept the unwanted situations, the disease and the ending of life, was an act of 'giving up' and inviting death closer: *'if you're not fighting you're resigning*

yourself to it' (F 12). The words '*acknowledge*' or '*allow*' were tended by facilitators as a better way to frame acceptance in this setting of palliative caregiving and bereavement:

> *Acknowledgement, instead of acceptance, because acceptance becomes a dirty word...acknowledging that this is where you are. You don't have to like it at all but acknowledging that you are here is an important thing* (F 10).

Engaging with their experiences, particularly those characterised by hardship, disruption and complexity, was perceived as a very different and challenging approach for caregivers. One facilitator emphasised that mindfulness was the antithesis of traditional psychological approaches to helping people manage distress:

> *I'm not aware of anything - any other therapy that would be willing to sit there with what is being experienced. Everything - every other therapy - would look to remove or get rid of, prevent* (F 12).

Facilitators, in particular, acknowledged the courage that mindfulness asks of caregivers to engage with difficult emotional experiences in such intense end of life circumstances. They acknowledged and described mindfulness as requiring *'a lot of courage and patience to be able to sit with those uncomfortable emotions if they arise'* (F 6) but observed the benefits this could bring to caregivers.

A significant benefit from acquiring the ability to tolerate and engage with difficult experiences, perceived by facilitators, was the opportunity for caregivers to transform their relationship with the distress and difficulty in their lives:

> *Having painful experiences … is a good thing, then they've got the opportunity to become aware and have a relationship with and transform them, but if they and we*

> *get stuck in protecting them from feeling the problem, then I think there is no movement. There's no change. There's stuck-ness* (F 8).

Mindfulness was also perceived to enable caregivers to reframe previous assumptions that difficult emotions and experiences were 'wrong', 'too painful' to encounter or detrimental to coping. A facilitator working with bereaved caregivers, explained how mindfulness supported caregivers to reconsider how they approached their grief and bereavement:

> *After a while they [caregivers] have learnt to kind of know where anger or overwhelm sit and be able to go, just let it do what it needs to do…what they start to engage with is that they are not wrong. They are uncomfortable, but they are not wrong. They can talk about it. They can engage with it* (F 10).

Another perceived benefit of engaging with difficult aspects of end-of-life caregiving and bereavement was the enablement of a 'fuller', more holistic experience:

> *I think it helps the person to a richer and fuller experience because you know it is easy for us all to feel that we all only want the pleasant experiences of life, but to actually be present to the less desirable parts of life helps us actually to live a much fuller life, to appreciate life a lot more, to appreciate the time we have with the person* (F 6).

Facilitators used the words '*paradoxical experience'* to explain that 'being with' that which is difficult, offers caregivers a chance to engage with the joyous and positive experiences and emotions in that moment: '*great fear and distress is in the presence of great love and joy as well*' (F 7). This was perceived to challenge the binary view of experiences as either good or bad, right or wrong, wanted or unwanted, commonly adopted by caregivers. One facilitator likened this new learning as acquiring the ability to 'hold a pair of opposites':

> *They learn to know that pain and other things can exist at the same time. It doesn't have to be an either/or, that just because they're in pain doesn't mean they can't have moments of joy or calmness, that the two can sit there equally together* (F 10).

Ava gave voice to the value of moving from a binary stance towards learning to engage with the full range of experiences. She explained that, before learning mindfulness, her avoidant response of frequently turning away from difficult experience was met with the cost of also turning away from the positive aspects of experience: '*if you block one out, you block both out, which means it doesn't give you access to good moments*'. Ava further explained that mindfulness has provided her with an alternative approach of engaging with *'the mixture of things in experience':* the good and bad, without fear of becoming overwhelmed.

These findings demonstrate that mindfulness was perceived to provide caregivers with an ability to acknowledge, accept and engage with the full range of experience, including distress and difficulty. This was regarded as a very different approach to caregivers' more common response of avoiding, seeking to change or fight against difficult experience. Whilst challenging and calling for courage, the benefits of being able to encounter both difficult and positive aspects of experience were perceived to transform caregivers' relationship to their distress and difficulty and support a more holistic experience.

7.4 Connecting with and Caring for Self

'Connection with and caring for self' constitutes the third conceptual category found in this study relating to the benefits of learning mindfulness in the context of end-of-life caregiving. The significance of this benefit is framed against the strongly perceived

disconnect that caregivers have with the concept and practice of taking care of themselves and their own needs, as described in chapter five. The underpinnings of this 'self-care disconnect' were explained as resulting from caregivers' feeling invisible and that their needs were not a legitimate focus. As a result, caregivers routinely relegate their own needs of secondary importance (if considered at all), to instead fully focus on the person for whom they are caring. This category of 'connecting with and caring for self' is made up of two subcategories: self-care, connection and compassion, and considering, voicing, and recalibrating needs.

7.4.1 Self-care, Connection and Compassion

In the view of participants, one of the most powerful benefits received from learning mindfulness was acquiring a way to care better for themselves. As such, mindfulness was seen by participants to be a form of and vehicle for 'self-care'. The value of mindfulness, as self-care, was considered by caregivers as a particularly powerful and unexpected outcome for them, particularly as all had identified in some way that 'becoming' a caregiver had caused a substantial disconnect from their own needs and wellbeing: '*I was so caught up in caring for my sister, I'd stopped caring for me. Committing to this* [mindfulness course] *was an avenue to get back to caring for me'* (Gwen).

Caregivers articulated that a core part of caring for themselves, as fostered through the learning of mindfulness, involved a 'reconnection' with a sense of themselves beyond all the roles they play in life, including the caregiver role: *'It* [mindfulness] *helps me centre, so now I can be in touch with myself again'* (Ava). For many caregivers, mindfulness provided what they saw as the first opportunity in their lives to connect with themselves and to understand and appreciate their own needs and inner life. Lorna explained that before learning

mindfulness she had no concept or awareness of self: '*You hear that you have to know yourself…I didn't know such a thing* [the self] *existed'.* When prompted to speak more about this, Lorna pointed to the way in which gender had impacted her sense of self:

> *The life I had, was the life I had. Knowing yourself, I mean the woman wasn't very important in the scheme of things, except being useful to cook the meals and do all that…'I really know what that means now.*

Participants emphasised that mindfulness not only fostered a connection with themselves, but that this connection was characterised by increased self-compassion or learning to be '*kinder towards yourself*' (Lorna). This was regarded as a significant shift in the way caregivers often viewed and related to themselves. For example, facilitators spoke of observing caregivers to ordinarily level harsh and critical judgements of themselves in caregiving: '*the level of self-judgement is just incredible across the board'* (F 10); *'guilt, selfishness, beating yourself up sorts of behaviours that they tend to have'* (F 9). Mindfulness was seen to support caregivers to lessen these harsh self-judgements by focussing on self-care and compassion. Cultivating a compassion for oneself was perceived to be aided particularly by learning mindfulness in a group setting. Within this context, it was perceived that, in observing other's harsh judgements of themselves, caregivers actually learnt to be less judging and critical of themselves.

> *All of us do have a whole lot of negative thoughts going on that don't really serve us. In the mindfulness course they see other people suffering and judging themselves and they themselves wouldn't judge those other people and by virtue of that awareness, they realise not to judge themselves* (F 4).

Supporting caregivers to engage in self-care, to cultivate self-compassion and connect with a sense of themselves outside of the caregiving role, were clearly valued benefits of learning and using mindfulness in end-of-life caregiving.

7.4.2 Considering, Voicing and Recalibrating own Needs

Along with self-care, connection and compassion, mindfulness was perceived to bring further benefits to caregivers, including a greater capacity to consider and voice their own needs. For many caregivers, like Gwen, considering and giving voice to their own needs was '*a very new practice*'. Gwen explained that whilst learning mindfulness she felt empowered, for the first time, to voice her needs to her sister for whom she was caring. She gave an example of telling her sister what she needed, in order to manage her anxiety and stress should she be required to get her sister to hospital again in an emergency situation:

> *I said, I can't think clearly in that high stress situation. I need you to have all your paperwork in one spot so that I can just grab it and go. I need you to have a bag packed, because we don't know what the outcome of all this is going to be*.

One facilitator articulated the context and significance of this acquired benefit from mindfulness, as the value of being able to '*find a voice to talk about their own needs, in relation to caring for somebody, who is nearly always perceived as having greater needs than them'* (F 4). Other participants used the word 'assertiveness' to describe the way in which mindfulness enabled caregivers to express their needs *'where they feel more able to ask for what they need, be clear what they want'* (F 5). Gaining an increased ability to be assertive through the learning of mindfulness was seen as a counterpoint to the

vulnerability and disempowerment commonly experienced by caregivers, particularly in bereavement:

> *A lot of them will say to me, before this event happened* [death of care recipient] *…I was able to really stand up for myself. But now I feel like there's this top layer of skin has been stripped off and I'm just super sensitive all the time* (F 10).

Learning mindfulness, particularly in a group, by hearing other caregivers talk about their experiences and needs, was perceived to catalyse, validate and support caregivers to perceive their own needs as important and legitimate:

> *Oh, that's similar to what I've been feeling, but I haven't wanted to say because I feel sort of selfish, almost, talking about myself". That's been a very useful part of the group I think* (F 9).

Beyond voicing their own needs, caregivers also spoke candidly about how mindfulness enabled them to better balance meeting their own needs, alongside the needs of the person for whom they were caring. For example, whilst Molly stated always having had a strong sense of her own needs based on what she described as '*a life time of being a feminist',* she voiced considerable difficulty in balancing her needs alongside her husband's, in the context of end-of-life caregiving. Molly explained that mindfulness supported her to continually recalibrate this balance:

> *There are things that I have to give up and I am able to do that, like I was able to give up going to* [City] *next week. It was hard, but I was able. I am able to accept that, I hope* [laughs]*... Yeah so, I have to juggle things, but I am not going to give up on*

[long pause], *I mean looking after me, however that might express itself, as long as I can, I have to balance those two [own and husband's needs].*

Other caregivers also spoke of mindfulness supporting a recalibration of caregiver and care recipient needs. However, they also pointed to the challenges this evoked, particularly with regard to unsettling the deeply embedded view of care recipient needs being most important. For example, Gwen talked hesitantly about coming to regard her needs equally to the needs of her sister, as if it was taboo or not acceptable for her speak of her openly of her needs as equal to those of her dying sister:

Because she was the one with a deadly illness, her needs were greater than my needs. But I came to a better space, where my needs were equally as important as her needs.

In speaking about trying to establish a more balanced approach to caregiving, mindfulness appeared to support caregivers to consider and move towards a middle ground of calibrating both the needs of the person being cared for with their own.

The benefits of mindfulness in enabling caregivers to reconnect with and care for themselves and to give voice to their own needs, was especially moving, particularly when considered against the strongly perceived self-care disconnect, described in detail in chapter five, as a key feature of the caregiving landscape.

7.5 Strengthening Relationships

Along with mindfulness supporting caregivers to reconnect with and care for themselves, study findings identified *'a ripple-effect'* of enhanced or strengthened relationships with others. This is the fourth conceptual category of benefit from learning

mindfulness in end-of-life caregiving found in this study. This section explores this benefit through the following subcategories of 'enriching moments' and 'enhanced compassion'.

7.5.1 Enriching Moments

Mindfulness was spoken about as enriching moments of connection between caregivers and those they were caring for. Participants expressed that mindfulness provided '*more space to open up to thinking about the time they have left with the person being cared for, what they want to do together, what they appreciate' (F 1).* These quality moments of connection were regarded to be important both in terms of shaping the present moment, and in terms of positively influencing bereavement. For example, Ava talked about one particular evening that she sat around the fire with her husband. She explained how distressed and frustrated he was with the day's interactions with health services. Drawing on her mindfulness learning, Ava spoke of the power of inviting her husband to join her in that moment, to really look at and feel the flames of the fire and stop ruminating on the day's events: '*We both sat together and looked at and experienced the fire and let everything else go'*. She expressed having had a deep and painful knowing that there will come a time where '*everything will get really shitty*', because her husband's illness would progress, and he would die. Ava explained that those shared moments around the fire were important as they were happening. However, she also reflected that they would be even more important to her, when looking back later from the place of bereavement.

Whilst most caregivers spoke of using mindfulness practice to strengthen their relationships with the person for whom they were caring, two caregivers (Lorna and Ava) spoke of mindfulness enabling a 'reconnection' from a place of complete disconnection. For example, Lorna described finding it difficult to spend time with her husband because he

'*was getting really sick and he was just getting so cranky*'. In Lorna's eyes, mindfulness helped her to acknowledge, but '*not-take-on-board'*, her husband's frustrated responses as something that she needed to feel responsible for: *'to have compassion for him. But I stay apart from it'.* This shift in her approach enabled Lorna to spend time with her husband as opposed to pulling away from him at the end of his life: '*It worked. It worked. I could go over and sit with him'.*

Ava explained that prior to learning mindfulness she recognised that she had deliberately disconnected from her husband because of shifting into her professional role as a nurse, as opposed to her role of wife, in order to protect herself from the pain and grief of confronting her husband's terminal illness:

> *I think part of me was turning into nurse Ava, not wife Ava, probably because I'm still hurting with loss. I couldn't bear the thought of losing him and so I was disconnecting with him. Because it's better to do it now so it doesn't hurt so much… it was a way to cope, so if you put a uniform on, you shut everything else out and you just exist.*

Ava cried as she reflected on her disconnection from her husband as '*the worst possible thing to do'* and explained that it was mindfulness that enabled this stark realisation: *'One of the weeks at mindfulness I realised that that's where I'd been at, and I was pretty devastated that night'.* She described, however, that mindfulness assisted her by shining a light on her disconnection with her husband and supported a conscious decision about how she wanted to engage with her husband. In doing so, Ava regarded mindfulness as having provided her with a way to heal this disconnect*: 'it enabled me to get Mark back, and to get our relationship back'.*

7.5.2 Enhanced Compassion

In addition to mindfulness offering the benefit of enhancing caregivers' own self-care and capacity to be compassionate towards themselves, findings indicate that this compassion extended to relationships with their terminally ill family member or friend. Participants used different descriptors to explain this. '*Increased compassion'* was one descriptor used frequently by facilitators (2, 5, 4, 10), stemming from caregivers first having learnt to be more compassionate towards themselves as outlined in the previous findings of this chapter:

> *I think if they can give themselves a bit more compassion, there's a good chance they can actually probably be a bit more patient and compassionate with whom they are looking after* (F 2).

Caregivers explained how mindfulness supported an enhanced compassion for their significant other by helping them feel less overwhelmed by their own experience:

> *In my observations of myself, that's where mindfulness and meditation have helped the most – to be able to be more compassionate, I guess. Notice what's going on in other people and respond to it in a way that's helpful, without being overwhelmed myself* (Sarah).

In talking about enhanced compassion, other caregivers and facilitators used the term 'more loving'. For example, one facilitator spoke of observing how a male carer attending a group mindfulness course with his terminally ill wife, had become evidently more connected and affectionate to her: *'he kind of got more and more loving as the eight weeks went through*' (F 2). Along with descriptors of increased compassion and being more loving, participants

conveyed that mindfulness enabled more considered communication between caregivers and the person they were caring for:

> *There's times where I will just, and it might only be for a minute or two, I will just, obviously not while I'm facing him, but if we're sitting side by side on the couch or something, I will just close my eyes and start* [to practise mindfulness*] just to calm me…It* [mindfulness] *stops me from reacting. It calms me enough that I can have a conversation about it, with a little bit of tact. I've never been great with tact* [laughs] *but the mindfulness does – it pulls me back. It calms me enough that I can process the situation and then approach it in a way that I know is not going to upset him or make things worse* (Laura).

Enhanced quality of caregiving was also advanced by both mindfulness facilitators and caregivers in this study, as a benefit of learning mindfulness. Molly expressed that '*mindfulness helps me to do the looking after Peter stuff without feeling resentful or judgemental or those things'.* In another example, a facilitator reflected on a male caregiver, who after learning mindfulness, provided care that was more 'in-tune' with the needs of his terminally ill wife:

> *He* [carer] *is more self-aware and less bullying - less pushy. He's allowed her the quiet space now…He's letting go of the need to hurry her and take her places out in the wheel chair that she just can't bear…he's come on board to realise the need for the stillness and the quietness that she has* (F 3).

Other facilitators (1,5,12) drew connections between caregivers gaining an enhanced ability to care for themselves and enhanced care for others*: 'if they are balanced in the care of themselves, they're more balanced in their care they provide to others'* (Fac 5).

These findings demonstrate that a core benefit of mindfulness, experienced by the participants in this study, was helping caregivers to develop stronger, more compassionate connections with the person for whom they were caring and to provide more considered, in-tune care.

7.6 Realising a Resourceful and Empowered Self

This fifth and final category detailing the value and benefit of mindfulness is 'Realising a resourceful and empowered self'. It explains the fundamental consequence of the varied processes and benefits of learning mindfulness, previously detailed in this chapter. Whilst it could be argued that the concept of empowerment is threaded throughout most of the categories in this theme, it also emerged, in analysis, to constitute a large and distinct entity in its own right. This final category presents how the gaining of a resourceful and empowered sense of self was regarded by participants to be at 'the heart of' or to represent the quintessential value of mindfulness in end-of-life caregiving. It is constituted of two key categories: 'Coping and empowerment' and 'Encountering loss: a new grief narrative'.

7.6.1 'Coping' and Empowerment

Whilst sharing the view that mindfulness cultivates an increased sense of resourcefulness, facilitators and caregivers spoke of this in very different ways. Caregivers used the word 'coping' extensively when speaking about the way in which mindfulness engendered a sense of self-belief in their own resourcefulness to manage the intense challenges of caregiving. The significance of this acquired sense of being able 'to cope' arose against a strongly perceived absence of personal agency, prior to learning mindfulness.

Molly, for example, explained that before learning mindfulness she was very vulnerable and fearful of the caregiving journey that lay before her: '*I didn't feel like I was able to cope with it and I was very scared about where it was going'.* Molly's experience was that '*life got easier'* after learning mindfulness, enabled by a growing sense of personal agency and resourcefulness to cope with the challenges of caregiving:

> *People who look at my situation said to me "gee that must be really hard" and it used to be really hard…but now I am managing, you know I have got a sense that I can cope with this.*

Coping, for Molly, was particularly aided by learning to accept, as opposed to fighting against her husband's illness: *'it's bad enough that he's really sick, without me making it even worse by railing against it and getting cranky about it'.* Gwen stated that mindfulness '*kept me going'* in the context of caring for her sister. She explained that mindfulness helped her move from a frozen state induced by stress, into a space in which she was able to function and cope again:

> *The stress is immobilising for me. There's a fight, flight and freeze. For me it's freeze. It immobilises me… but it wasn't a position I could be immobilised in…*so *it* [mindfulness] *let me get out of that freeze state and come back into a functioning state again* (Gwen).

Gwen further gave a specific example of going to the hospital chapel to practice mindfulness whilst visiting her sister during her treatment. She spoke of experiencing mindfulness as restorative and bolstering a feeling of being able 'to cope': *'it was a good place to sit and just practise some mindfulness and bring the stress levels right down, back to the point where you can cope with things'.* Bill expressed that the '*little moments to rest in*', afforded

by his mindfulness practice, enabled him to cope with and navigate his heavy experience of bereavement. In Bill's experience, grief had become more intense and difficult to manage as time went by following his wife's death: '*it's getting harder, not easier'*. In such a context, mindfulness has provided the only moments of ease and calm for Bill, outside of sleep, as he has worked through the acutely felt absence of his wife of sixty-eight years.

Whilst caregivers consistently used the word 'coping', facilitators more often used the words such as '*empowerment*' (F 10,4) and '*self-efficacy'* (F 8) or '*less helpless',* (F 8,7,4), to communicate a sense of enhanced caregiver agency or resourcefulness to deal with difficult experience, as a result of learning mindfulness:

> *Their greatest sense of self and empowerment grows stronger and stronger and stronger because they're doing it for themselves. The helplessness starts to go down, down, down, down because they know they can empower themselves* (F 10).

Similar to caregiver narratives, embedded in the central descriptors used by facilitators to describe empowerment, were the words 'coming to', 'moving to' or 'acquiring', which conveyed a sense of caregivers having been somewhere else in regard to agency: a place of less or no agency.

Restoring a sense of control, in a situation that often felt out of control, was another descriptor used to describe increased caregiver agency, fostered through learning mindfulness. One facilitator explained, '*the very fact of coming back to the present is a form of agency, or if you like control, and it's a doing action. It puts you back in the driver's seat'* (F 9). Caregivers, like Laura, also used the descriptor of mindfulness helping them to feel more in control and better able to meet the demands of caregiving that had previously felt too overwhelming: *'It helps me manage day to day. It really does'.* These positive effects for

Laura reached into all quadrants of her life including parenting and work-related challenges in addition to caring for her husband. She experienced these wide range of effects as profound, *'it's not just about when I'm at home or when I'm at work or when I'm spending time with my son and he's being a little bugger. It is, it's huge' (Laura).*

Both caregivers and facilitators (5, 12, 1, 7) also talked about the way in which mindfulness supported caregivers to '*trust themselves more' (F 5)* and gain an increased sense of self-belief. One facilitator expressed, in a particularly nuanced way, how mindfulness supported caregiver belief in one's ability to cope with and manage what was often regarded as an 'unmanageable' situation of facing the death of someone they loved:

> *For caregivers and for families it* [mindfulness] *opens up a possibility that we can do this. We often just think this is just not possible. I just can't do it. How often do we hear people say, "I just can't do this anymore? It's* [mindfulness] *just enabling the suggestion that maybe this is possible. Maybe I can do this* (F 7).

The facilitator talked further about how mindfulness engendered a sense of hope that caregivers could manage what felt like an unmanageable situation:

> *Hope seems to be a constant discussion with palliative care. It* [mindfulness] *opens up the hope, not that things will change but the hope that we can do this. That it is possible for us to do this journey. I mean that's what we hope for. Not that anything will actually change, and reality is different, but we hope for the capacity to just be able to do this. If we get a glimmer of "I can do this" and I can do this with just a little bit of grace and love and joy, then it is possible - then it's okay. I think that's what this [mindfulness] offers* (F 7).

Jason similarly talked about how mindfulness fortified a sense of strength and self-belief to encounter difficult moments whilst caring for his friend at the end of his life. He voiced gaining a sense of, '*I can do this'*, however difficult the moments might be. Jason contemplated that without mindfulness, it was very possible that his projected fears of the future or rumination on past events would have overwhelmed him and his ability to cope:

> *I can only speculate that if I didn't have that understanding of temporal anchoring* [being in the present moment] *that it probably would have flooded my resources and entire day to things that haven't happened yet or memories of things that have happened.*

Sarah, like Jason, emphasised that mindfulness helped her to steady herself in the face of strong emotions that at times threatened to overwhelm her whilst caring for her mother. For Sarah, mindfulness was regarded as an important source of strength in caregiving: *'to me that's been important …because I don't feel like I would have that strength otherwise'* (Sarah).

Mindfulness was also spoken about as enabling caregivers to reconsider themselves as having internal resources and strengths, as opposed to locating the expertise in others, especially health providers. Facilitators talked about this using the term, '*self as expert',* (F 10,7,8,9,5,13). They explained that this experience of 'self as expert' or having an inner resource was very new and different for many caregivers with whom they had worked and one that offered significant benefit:

> *A lot of them* [caregivers] *think - well the expert model has been around for ages. We're [health care providers] the expert and therefore you have to listen to what we say. So now we're teaching them that actually, no, you're the expert. I'm just here for*

> *a very small smidgen of your life. The rest of the time actually, you're knowing how to do that* (F 10).

Whilst facilitators used the phrase 'self as expert', caregivers spoke of this in terms of gaining a different view of themselves as being stronger than they had previously thought. For example, Ava spoke of how mindfulness enabled a realisation for the first time in her life, that she was resourceful and had the skills to cope with difficult circumstances. She expressed that mindfulness powerfully engendered a sense of being an active and effective participant in her own self-healing: '*I don't know, having someone listen to you is really lovely, but if you don't process it yourself and you don't heal in yourself, it doesn't heal'.*

Perhaps the most poignant examples of mindfulness fortifying a sense of resourcefulness can be found in the stories of Ava and Lorna, who both shared how mindfulness shifted their suicidal ideation. Ava powerfully attributed mindfulness as having prevented her from taking her own life, which she described as having brought her back from *'being on the edge of a cliff'* to a place where she could cope*:*

> *Look, I reckon it saved me* [strained laugh] *because life was pretty tough there for a while, you know. Seeing Mark through and then I think, well I'll go too because I can't cope with anymore.*

Ava described this profound impact of learning mindfulness in the following way: *'it let me appreciate life again. I don't know how to say how huge it is – being able to do that*'. Like Ava, Lorna explained in careful and resolute detail how she felt that learning mindfulness had saved her life. She candidly disclosed reaching a very low and depressed state when her husband became increasingly unwell:

I was such a mess… If I hadn't ever done it [mindfulness], *I wouldn't be having a life…I could have killed myself. There was no meaning at all.*

Lorna explained that mindfulness had enabled her, for the first time in her life, to manage her depression and in doing so, cope better with the challenges of caregiving and bereavement. Lorna further stated that she's no longer fearful of her depression escalating because mindfulness has provided her with the resources to cope with it: '*There's always a possibility, but I'm not scared of it. I'm not worried about it. I feel I can handle it if it comes on. I'll know what to do'.*

7.6.2 Encountering Loss: A New Grief Narrative

Whilst mindfulness was regarded to support coping across a diverse range of end-of-life caregiving experiences, enhanced coping in relation to grief and bereavement specifically, was strongly articulated by facilitators (F 1,3,11,6,5,8,9,7,10): *'mindfulness, I think, can help enormously with grief'* (F 6). One facilitator in recounting her own personal bereavement stated that, '*It was the mindfulness that got me through, nothing else. It was the mindfulness'* (F 10). Similarly, all four of the caregivers whose significant other had died, expressed that mindfulness supported them to cope with both their anticipatory grief and bereavement. Both Bill and Jason experienced mindfulness as a way of steadying themselves in the face of strong and often overwhelming grief. For both men, mindfulness enabled them to '*hold it together*' (Jason) and '*keep it together'* (Bill), against the fear of 'falling-apart' after the death of significant people in their lives. For Lorna, regular and intensive mindfulness practice was used for some months to cultivate a level of acceptance that her husband was going to die. Lorna explained experiencing a sense of acceptance and peace in relation to her husband's death, which she attributed to having learnt mindfulness:

> *I just felt at peace because I was learning to be at peace and not letting anything take over from that, like yearning or all that. If I hadn't done that* [learnt mindfulness)*, I would have been in that grave with him*.

The experience of bereavement was described, by facilitators, as another intense and disorientating landscape that opens up beyond the caregiving landscape, previously described in Chapter Five:

> *People find themselves in this place and there's lots of words that will describe that, hell, the place in between, whatever you want to call it. They will find themselves there. They will look around and go, "I have no idea where this is". So, they've got an L-plate, not even knowing how to drive in this place and there's no GPS. There's no sense of direction…everything they have known about themselves has gone out the window* (F 10).

In this context, facilitators had observed mindfulness to help caregivers navigate this additional bereavement landscape by offering a new way of approaching grief. This involved '*being with'* and '*opening up to*' grief, as opposed to the dominant social messages which encouraged people to turn away from grief: '*many people are told how they should be doing it* [grief). *Put it away or stop being selfish or get over it'* (F 10). One facilitator explained this more 'allowing' approach to grief, afforded by mindfulness, constituted a new narrative:

> *Mindfulness practice allows a creation of a narrative that's a more fully encapsulating, and maybe more comforting narrative as well, but paradoxically by facing some difficult stuff gently, gently, gently as they open up to it…* [mindfulness] *gives them real encouragement and courage to be present through grief* (F 9).

Facilitators emphasised that whilst grief remained, mindfulness, by supporting caregivers to engage with their grief in this different, more allowing way, facilitated a shift in caregivers' relationship to their grief. There was a perceived increased sense of being able to encounter and work with it: '*I think with mindfulness you can be in the presence of the grief…you can be in the presence of pain'* (F 3). Mindfulness was perceived by another facilitator to enable caregivers to have a fuller experience of bereavement. He shared his own experience of grieving his mother's death prior to learning mindfulness and then grieving his father's death after having learnt mindfulness:

> *I had an experience of my mother passing away and not feeling a lot of emotion and being a bit surprised by that… it was a little bit strange. But then I did the mindfulness. Then several years later, my father died. It was a much different experience. A much more powerful, emotional experience, which I was much more connected to and felt more - it felt real. So, it was full emotion, full grief and full effect of that in amongst the other, the real rollercoaster ride of what happens from grief. I felt that it lasted for a shorter period I think - and I got through it very well, I thought. I don't know if that was mindfulness, but it seemed very different to my mother's passing* (F 1).

This finding of 'realising a resourceful and empowered self' in times of grief, bereavement and caregiving in its entirety, expresses the quintessential value or consequence of the processes and benefits of learning mindfulness addressed in this chapter. It is significant, that this sense of personal agency arises against a context in which caregivers commonly feel very disempowered, uncertain and concerned about their ability to manage the difficult terrain of caregiving. Mindfulness was spoken about by participants in this study, not in

terms of its ability to vanquish or even ultimately diminish the difficulties and heartache of the caregiving landscape, but rather, how it can offer caregivers a fortified sense of resourcefulness or ability to cope with a previously perceived 'un-cope-able' situation.

7.7 Chapter Summary

This chapter has detailed both caregivers lived experience of value and benefit from learning and using mindfulness in the context of caregiving and the perceptions of mindfulness facilitators. Rich and complex descriptions of benefit were presented under five key categories. 'Repositioning of self' represented the first key benefit, which in essence described brief, but important movements from being entangled and overwhelmed by thoughts, feelings and projected fears of the future, into a more grounded, clearer space. Through this process of repositioning themselves, caregivers gained additional benefits. These included, learning to engage with difficult experiences, as opposed to avoiding them, connecting with and caring for themselves, and experiencing strengthened relationships. The quintessential value of these interwoven benefits was gaining a sense of realising a resourceful and empowered self or a sense that 'I can do this'. The magnitude of this benefit was largely unexpected by caregivers and not easily understood in terms of how mindfulness produced these benefits.

These findings of the process and benefit of learning mindfulness in caregiving contain strong and vivid description of 'gain': gaining a more grounded space in which to rest and see clearly, gaining connection with self and others, gaining a sense of strength and resourcefulness. This sense of gain was juxtaposed sharply against how participants described the experience of end-of-life caregiving, which was characterised as a heavy landscape of loss.

The next chapter, ‘Discussion’, marks the move to the final Part of this thesis: Part V. The Discussion will present the theoretical model developed in this study, to explain the experience of learning and using a mindfulness-based approach in end-of-life caregiving.

PART V:

A GROUNDED THEORY MODEL AND ITS IMPLICATIONS FOR RESEARCH AND PRACTICE

Part V of this thesis builds on the findings' chapters of Part IV. It comprises two chapters: Chapter Eight 'Discussion' and Chapter Nine 'Conclusion'. The aim of Part V, the final section in this thesis, is to present the theoretical model constructed in this study and discuss its implications in relation to the existing literature as well as future research, policy and practice. The strengths and limitations of the present study are additionally addressed.

This final part of the thesis concludes with a personal reflection on the research process and my layered learning. It offers a fitting book-end to the beginning of this thesis in which I situated myself personally, professionally and philosophically, in relation to this study.

CHAPTER 8

DISCUSSION

8.1 Chapter Introduction

This chapter presents and discusses the theoretical model developed in this study to explain the experience of learning and using a mindfulness-based approach in end-of-life caregiving. The research problem and study aim are briefly revisited, before discussing each component of the theoretical model in relation to the existing literature. The contribution this model makes to new knowledge and its implication for clinical practice and further research are advanced.

8.2 Revisiting the Research Problem and Study Aims

Despite a global consensus of the need to support informal palliative caregivers in their critical role of providing end-of-life care, there is a paucity of evidence-based support interventions. Considering the well-documented adverse impacts of caregiving, this provides an unsettling view: so much distress, yet so few interventions. Of those interventions that have been trialled and evaluated, the range remains narrow in relation to caregivers' holistic needs and are still primarily concerned with enhancing preparedness and self-efficacy to provide care to others. Specifically, there is a lack of interventions that focus on cultivating caregiver capacity and willingness to care for themselves and their own needs in the face of significant challenges in end-of-life caregiving. Whilst emerging research on the potential for mindfulness-based interventions (MBIs) to support informal palliative caregivers has indicated benefit, most studies have adopted a quantitative approach to inquiry, leading to

a lack of nuanced understanding of what it is like and what it means to learn and use mindfulness in this setting.

Using a qualitative approach and constructivist grounded theory methodology, the aim of this study was ***to provide an in-depth, conceptual understanding of the experience of learning and using a mindfulness-based approach whilst caring for a family member or friend at the end of life*.** Based on the identified gaps in the literature outlined above and in Chapters Two and Three, this study began with two main research questions:

1. *How is learning and using a mindfulness-based approach in the context of end-of-life caregiving experienced and described, including potential for value and benefit, as well as adverse effects and harm?*
2. *What are the key considerations in developing and providing mindfulness-based approaches for informal palliative caregivers and why are they important?*

One additional question arose during data collection and analysis, which became important to the developing theory:

3. *How do informal palliative caregivers engage with the concept and practice of considering and taking care of themselves and their own needs?*

The focus of this present study and its attendant questions were a significant departure from existing literature which has primarily focused on quantifying the effects of MBIs in this setting.

8.3 Development of a Theoretical Model

Findings from this study have been used to develop the first known theoretical model in the field of mindfulness-based intervention research in the informal palliative

caregiving setting. *'The Experience of Learning and Using a Mindfulness-based Approach in End-of-Life Caregiving: A Theoretical Model'* is grounded in the emic perspectives of caregivers and mindfulness facilitators and includes the voices of those often not recruited to research of this kind, such as rural caregiver populations and those not connected to palliative or supportive services. The model proposes that end-of-life caregiving involves experiencing 'a world disrupted' - a sense of being torn from a known and familiar world and landing into a disorientating landscape characterised by loss and challenging terrain to navigate. Despite a deep-seated sense of 'struggling to cope' in this landscape, caregivers experience a profound disconnection with the idea and practice of self-care.

The process of learning and using mindfulness in this disrupted and disorientating landscape of end-of-life caregiving requires consideration of how caregivers engage with mindfulness, the supportive factors that enable challenges to be overcome and how to mitigate potential for adverse effects. These factors are considered important, as learning and using mindfulness in the context of end-of-life caregiving is not without its challenges.

Whilst the disorientation and difficulties of the caregiving landscape persist, mindfulness-based approaches provide caregivers with brief, but important moments of re-positioning themselves in relation to their experience, self and others. These movements or re-positionings are characterised by increased engagement, compassion, connection and a sense of being able to cope with a previously perceived 'un-cope-able' landscape of caregiving. In doing so, mindfulness-based approaches can offer caregivers a new form of respite: one that doesn't require separation from the care recipient to experience restorative moments that can enhance their resourcefulness to care for themselves as well as their significant other. Figure 8 below provides a visual depiction of this model.

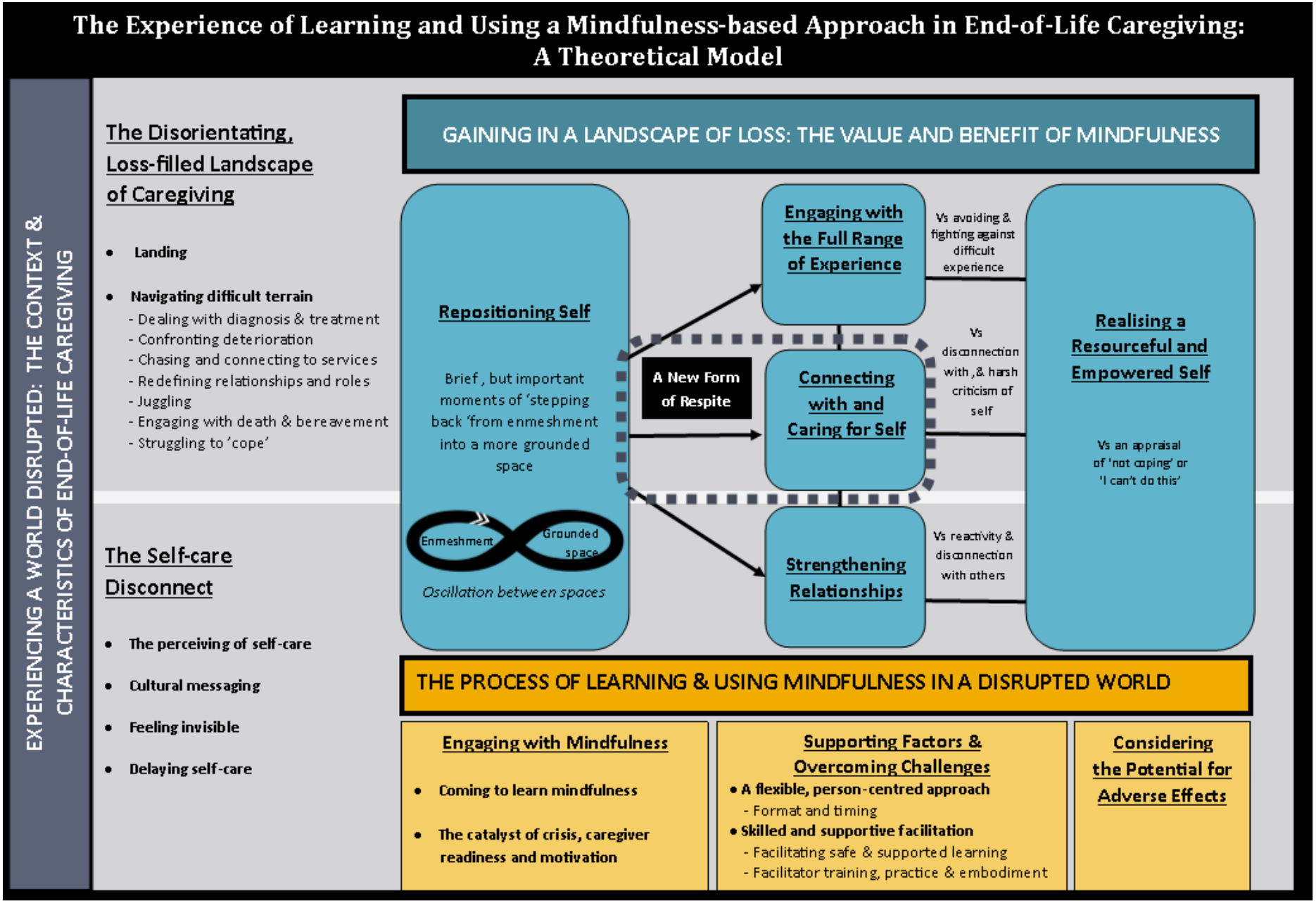


Figure 8: The Experience of Learning and Using a Mindfulness-based Approach in End-of-life Caregiving: A Theoretical model

This next section will outline the three overarching processes of this theoretical model and their salient points in relation to the existing literature.

8.4 Unpacking the Theoretical Model (Process 1)

This section addresses the first overarching process articulated in the theoretical model, 'Experiencing a World Disrupted: The Context and Characteristics of End-of-Life Caregiving'. Specifically, it focuses on the idea of 'disruption' and the key challenges of end-of-life caregiving. These include landing in and navigating difficult terrain in a disorientating, loss-filled landscape and experiencing a pervasive self-care disconnect. This first overarching process has been lifted from the theoretical model and is provided here for reference in Figure 9 below.

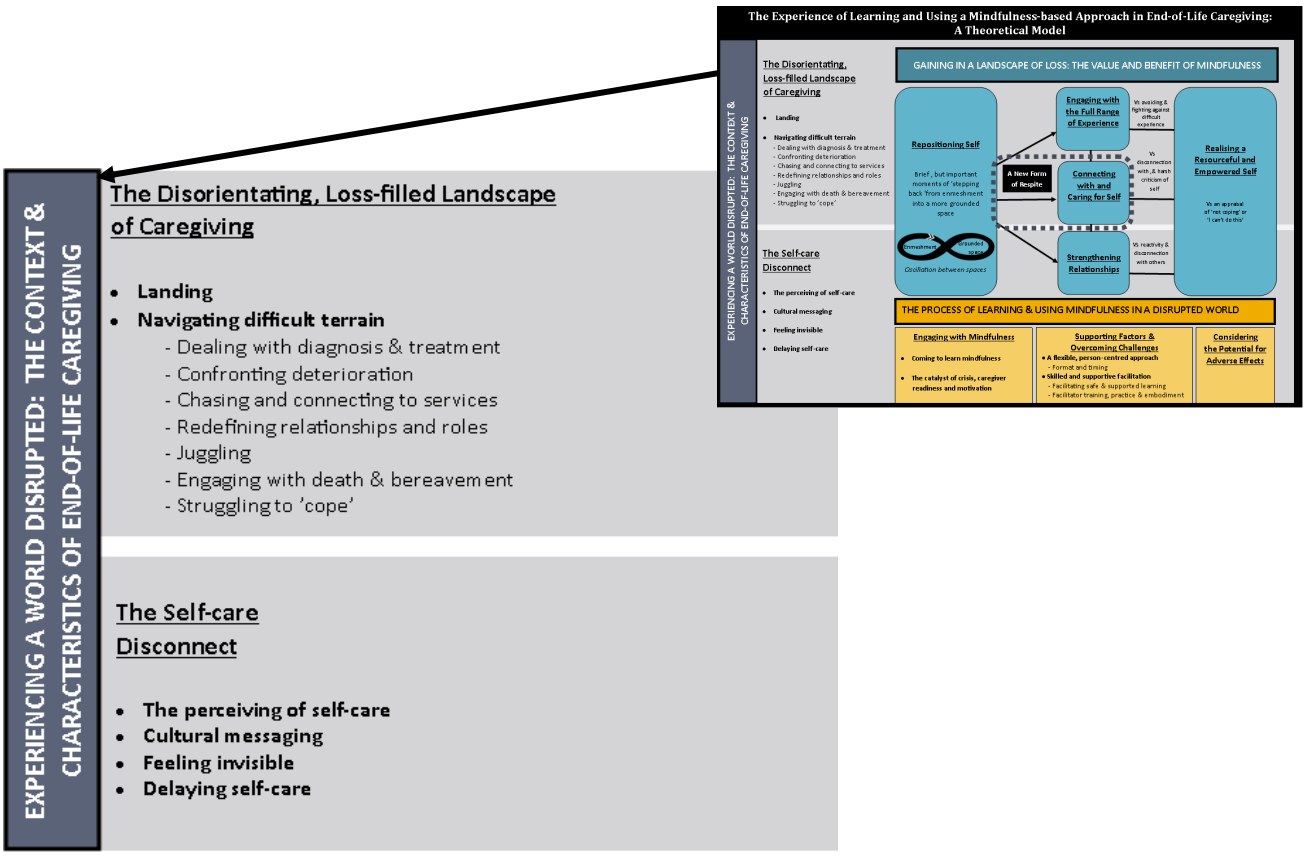


Figure 9: The First Overarching Process of the Theoretical Model

8.4.1 The Disorientating, Loss-filled Landscape of Caregiving

A strong sense of disruption was a key characteristic of end-of-life caregiving, experienced by caregivers in in this study. Descriptors of caregiving as akin to landing in a 'disorientating', 'uncertain' landscape, attunes us to the magnitude of disruption and disturbance that end-of-life caregiving can bring to what was known and familiar in one's life. These findings resonate with a range of existing studies which have identified similar caregiving experiences (Dahlborg Lyckhage & Lindhal 2013; Duggleby et al. 2017; Gyles & Higginson 2009; Jowsey, Strazdins & Yen 2016; Martin, Olano-lizarraga & Saracíbar-razquin 2016; Penrod, Hupcey & Shipley 2017; Waldrop, Kramer & Skretny 2005). For example, the finding of caregiving as 'an imploded world' (Glysels & Higginson 2009) or as 'a permanently altered life' (Martin, Olano-lizarraga & Saracíbar-razquin 2016). More recently, a meta synthesis by Duggleby et al. (2017) of 72 caregiving studies depicts significant transitions in the process of caregiving, including the process of seeking to 're-define normal' because of disruption caused in end-of-life caregiving. The clear finding in this present study, of illness creating a fracture or disruption in normal life patterns, relationships and 'core assumptions about the world, the future and self' (Reeve et al. 2010, p 179) is prominent in the conceptual theory of 'Biographical Disruption' advanced by Bury (1982). Biographical Disruption is a significant sociological lens which has been used to analyse the patient experience of chronic illness:

> Chronic illness is precisely the kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves a recognition of the worlds of pain and suffering, possibly even death, which are mostly only seen as distant possibilities or the plight of others. In addition, it

> brings individuals, their families and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support (Bury 1982, p 169).

Whilst the idea of biographical disruption is most commonly applied to patients, the findings from this study of a pervasive sense of life disturbance presented by caregivers, indicate this theoretical approach could be extended to also better understand the experiences of informal palliative caregivers. In a recent phenomenological study by Jowsey, Strazdins & Yen (2016) of 25 caregivers caring for a family member with a chronic illness (88% female, 76% caring for a spouse) salient themes associated with a sense of biographical disruption were identified. The emergence of associated concepts of 'biological flow' (Faircloth et al. 2004; Reeve et al. 2010) and 'biological reconstruction' (Williams 1984) are also relevant to this study, as they describe how individuals can adapt to disruptive events and maintain a sense of meaning and continuity of self. These concepts may offer value in exploring the experiences of informal palliative caregivers in future research.

Beyond describing the experience of 'landing' in a disorientating, loss-filled caregiving landscape, findings elucidated a range of challenges that require negotiation by caregivers in this new space. The powerful metaphorical description of 'navigating difficult terrain', generated in this study, may provide a helpful way of conceptualising and talking about the experience of caregiving and its varied challenges. It serves to make visible, the ordinarily invisible private struggles and losses often encountered by caregivers. A similar metaphor of 'navigating uncertain waters' emerged as a key theme in another grounded theory study which explored the end of life transitions of 28 older rural caregivers caring for family members with advanced cancer in Canada (Duggleby et al. 2010). It is interesting that

the in vivo terminology of 'navigating' and environmental-based descriptors of caregiving as a 'landscape' or 'seascape' were identified in this, as well in the study by Duggleby et al. 2010. This may reflect the fact that both were grounded theory studies preserving the voice of participants and recruited largely rural caregiver participants who may possess a greater infinity or connection with the physical environment around them.

This present study identifies specific challenges characteristic of end-of-life caregiving, which are also reflected in the extant literature. These include difficulties in securing a diagnosis (Martin, Olano-lizarraga & Saracíbar-razquin 2016), navigating treatment (Koenig Kellas et al. 2017), feeling distanced from the treatment decisions of their significant other (Preisler et al. 2018) and encountering patient deterioration (Anderson & White 2018; Beng et al. 2013; Milberg, Strang & Jakobsson 2004) or 'witnessing diminishment' (Sinding et al. 2003). The difficulty expressed by caregivers in this study of '*confronting reality*', particularly talking with their significant other about the terminal nature of their illness, is also echoed in the literature (Proot et al. 2003; Sinding 2003). However, this study serves to build on and extend this existing knowledge and to point to important future research by bringing to light the following key characteristics of end-of-life caregiving.

A key characteristic of end-of-life caregiving, as described in the existing literature and echoed in this study, is the challenge caregivers face in navigating varied types of loss and grief (Anderson et al. 2016; Dumont, Dumont & Mongeau 2008). The literature often presents loss in terms of two primary categories; anticipatory loss and loss in terms of bereavement. The findings of this study indicate a multitude of losses outside of these two categories. For example, the range of caregiver losses elucidated in the present study

included: (1) the loss of their known 'world' before caregiving, (2) the loss of health and altered relationship with their significant other, (3) loss of their own identity as they negotiated 'becoming' and coping with 'being' a caregiver, and (4) loss of a planned future. In this study, two caregivers also experienced the loss of their own home and one caregiver, the anticipated loss of home, due to no longer being able to manage their rural properties on their own as their spouses became progressively unwell. Notwithstanding the immense changes that can befall the home space due to increased visitors, visiting services, and having to accommodate equipment (Carlander et al. 2010; Duggleby et al. 2017), the home-space in the palliative literature is regarded as significant for caregivers and those for whom they care. It is variably described as enabling continuity of identity and belonging (Scannell & Gifford 2010), a sense of normal life (Williams 2002) or a 'place of comfort and ease' (Horsfall et al. 2017, p 61). The significant experience of caregivers having to sell and move from their homes, many of whom had lived there most of their lives, whilst noted in other studies (Ugalde 2011), has not received a significant amount of research attention (Carlander et al. 2010).

Further elucidating the experience of loss, the findings from this study shed light on caregivers' experience of the death of their significant other and their ensuing bereavement as an ongoing process: *'I will probably be grieving for her* [wife] *until the day I pack it in myself'* (Bill). These multiple and cumulative experiences of loss and grief appeared to have heavily underscored caregivers' sense of their world being disrupted and pulled apart, with many of the known, loved and valued elements of it being stolen away. The findings therefore indicate that, while 'loss' is undeniably a key characteristic of end-of-life caregiving, it is not a single construct but rather a term that can include many dimensions and experiences.

Another key characteristic of end-of-life caregiving identified in this study, involved the idea of having to sustain the act of '*juggling*' as a caregiver. This powerful and useful metaphor served to emphasise the continued energy, focus and attention required to balance caregiving alongside other life roles. Other studies have identified similar challenges faced by caregivers in having to balance multiple competing demands and roles (Breen et al. 2018; Cagle et al. 2011; Dahlborg Lyckhage & Lindahl 2013; Duggleby et al. 2017; Jo et al. 2007; McDougall, O'Connor & Howell 2018; Smith 2009; Waldrop et al. 2005). Many studies have indicated formal support from service providers can assist caregivers to better manage or juggle the tasks of caregiving and other responsibilities (Duggleby et al. 2017). However, a key finding in this study was that all the caregivers interviewed were largely juggling caregiving on their own, having either not yet connected to services or had only connected with services towards the very end of their significant other's life. Absence from, or late connection to services has been identified in the literature as an issue, particularly for caregivers caring for people with non-cancer illness such as end-stage organ failure and dementia (Diop et al. 2017), as well as for people in rural areas (Robinson, Pesut & Bottorff 2012). This has implications for caregiver health and wellbeing as studies have found that the use of support services such as home-based palliative care services and hospice care can decrease caregiver burden and improve mortality outcomes (Christakis & Iwashyna 2003; Guerriere et al. 2016). Service support has also been found to reduce isolation and a sense 'of caring in the dark' (Andershed & Ternestedt 2001) and is a critical component to assisting caregivers to adapt to the disruptions and transitions in end-of-life caregiving (Duggleby et al. 2017). It is of some concern, therefore, that for the caregivers in this study, connection to and receipt of support services came very late in their caregiving experience. Non-connection with services for caregivers in this study, similar to findings in other studies, was

underpinned by caregiver uncertainty about the legitimacy of their support needs (Aoun et al. 2015a), lack of knowledge of available services (Grigis et al. 2006), services being declined by the person for whom they were caring (Duggleby et al. 2010; Ronaldson & Devery 2001), services being promised but not delivered and, in some cases, the lack of available services (Robinson, Pesut & Bottorff 2010). For example, in the site of this study, (North West Tasmania), there are no hospice or inpatient palliative care units, only community palliative care teams. Difficulty in accessing services was found to significantly impact caregiver experiences, health and wellbeing because of limited support: '*It's just me'* (Laura).

'*Struggling to cope'* constituted another key characteristic of end-of-life caregiving identified in this study. Caregivers spoke of being charged with the responsibility to lead and make things better for the person for whom they were caring. However, inwardly they expressed feeling ill-equipped and overwhelmingly fearful to do so. Despite these strong concerns, caregivers projected 'coping' for the benefit of others, thus concealing their sense of 'not coping'. A range of other studies have similarly found that caregivers project strength and being in control for the benefit of others (Brobäck & Berterö 2003; Martin, Olano-lizarraga & Saracíbar-razquin 2016; Oyebode, Smith & Morrison 2013; Proot et al. 2003; Ugalde, Krishnasamy & Schofield 2012). The implication is, that this deeply felt sense of vulnerability, concealed beneath a projected coping for the benefit of others, doesn't unveil or make visible caregivers own support requirements and care needs. Additionally, this approach does not facilitate connection to available supports. In a broader view, these concealed needs do not advance the development of more caregiver support programs.

Another key characteristic of the difficult terrain requiring navigation by caregivers in this study was coming to terms with their caregiver role. The finding of diverse identification with the term 'caregiver' among study participants similarly resonates with existing literature (Dahlborg Lyckhage & Lindahl 2013; Grande et al. 2009; Harding & Higginson 2001; Henwood, Larkin & Milne 2017; Molyneaux et al. 2011; Ugalde 2011). Whilst some caregivers came to identify as a 'caregiver', others strongly refuted this label, viewing themselves in terms of a continuing relationship, such as being a daughter, '*I see myself as her daughter'* (Sarah). While there were only two male caregivers in this study, gender appeared to shape the way in which caregivers viewed themselves in caregiving. For example, both men (Bill and Jason) defined their role in terms of function: '*I see myself as someone trying to make things better for her'* (Bill).

The finding of an 'evolving' carer identity, whereby people come into and sometimes out of the role of end-of-life caregiver, offers something additional to the literature, indicating that caregiver identity, if adopted, is not fixed. These findings of diverse identification with the term 'carer' contribute to existing calls in the literature to develop a more inclusive term to identify caregivers in practice and in research (Molyneaux et al. 2011). This study reinforces existing concerns that in the absence of a more accepted term by those who care for family members and friends, how do we identify and render support to 'caregivers' or engage them in research if they don't identify as such. The opportunity exists for more dynamic and progressive research to take up the challenge of exploring, in partnership or collaboration with caregivers themselves, a definition of a more accepted, useful term to support a more consistent and inclusive approach to practice and research in the field of informal palliative caregiving. This may lead to increased uptake and

engagement with services and supports for caregivers, which could result in improved caregiver and patient outcomes.

Another important finding in this study, relating to the challenging terrain encountered in end-of-life caregiving, is the experience of *redefining relationships and roles* in response to a palliative diagnosis. Due to diminishing care recipient capacity to undertake previously performed roles, a recalibration of the relationship between the caregiver and the care recipient was found to be required. This was explained by the caregivers in this study as a huge change for many and extremely difficult to negotiate. This ongoing sense of redefinition echoes the findings from other studies which emphasise the challenges of experiencing a lost sense of reciprocity and equality in relationships due to advancing disease (Dahlborg Lyckhage & Lindahl 2013; Duggleby et al. 2010; Jo et al. 2007; Martin, Olano-lizarraga & Saracíbar-razquin 2016; Waldrop et al. 2005). This suggests a need for more interventions to address the important aspect of interpersonal relationships that are affected alongside the more commonly addressed issues of physical and practical needs in end-of-life caregiving (Martin, Olano-lizarraga & Saracíbar-razquin 2016; Merluzzi et al. 2011; Ugalde 2011). There was one additional issue associated with the redefinition of relationships, characteristic of end-of-life caregiving, experienced by several caregivers in this study. Three caregivers with a health professional background (Jason, Sarah, Ava) experienced a significant tension between being perceived and related to by others in terms of their professional roles (nurse, doctor, psychologist), rather than their personal roles such as friend, daughter and wife. This gave rise to what caregivers constructed as unfair assumptions and expectations of them and a failing to see that this was a deeply personal experience with which they required support. Other studies have pointed to the issue of family caregivers with a health profession background facing additional challenges in their

caregiving role (Boumans & Dorant 2014; DePasquale et al. 2015). However, more research is required to determine how to ensure that within the health system, informal palliative caregivers with a health profession background are afforded the same care and support as any other family caregiver and not have their role assumed for them (Ward-Griffin et al. 2015).

The final characteristic of the experience of end-of-life caregiving, as portrayed by the participants in this study, was *the lack of positive description*. For example, beyond voicing feeling proud of being able to render care and support to a significant other at the end of their life and to honour their funeral wishes, descriptions of caregiving prior to learning mindfulness were largely devoid of reference to positive aspects of caregiving. This was somewhat surprising considering that this study adopted a resolve to stay open to and particularly search for positive, caregiving descriptors. This focus was founded on a recognition that many studies, in neglecting inquiry into positive aspects, have led to a skewed view towards the more difficult and problematic aspects of caregiving (Hudson 2004). One possible explanation of the limited positive descriptors of caregiving may be that much of the caregiver research in palliative care has recruited caregivers who are in larger metropolitan areas and already in receipt of palliative and other support services (Robinson, Pesut & Bottorff 2012). This contrasts with the caregivers in this study who were predominantly from rural settings and yet to be connected to services or had only received services towards the very end of their significant other's disease trajectory. It may also reflect that caregivers perceived the research interview in this study as an opportunity to voice the more difficult aspects of caregiving that they hadn't previously been able to share: '*You're only the second person I have talked to about this'* (Jason). Descriptions of positive caregiving experiences post learning mindfulness were anchored in caregivers' sense of

feeling more empowered and able to better manage the difficult situations they were currently, or anticipated, encountering and enjoying better connection and quality time with their significant other. Caregiving, however, was still largely portrayed as a disorientating, loss-filled experience.

8.4.2 The Self-care Disconnect

As shown in the theoretical model developed in this study (Figure 8), Process 1: 'A World Disrupted: The Context and Characteristics of End-of-Life Caregiving' contains a second conceptual category: 'The self-care disconnect'. The finding of caregivers' pervasive reluctance to take care of themselves and their own needs was striking, and resonates strongly with existing studies (Cain, MacLean & Sellick 2004; Carlander et al. 2010; Dahlborg Lyckhage & Lindahl 2013; Duggleby et al. 2010; Funk et al. 2010; Grande et al. 2009; Harding & Higginson 2001; Ugalde, Krishnasamy & Schofield 2012; Robinson, Pesut & Bottorff 2010). Whilst this self-care reluctance has been referred to in the literature, at least across the last three decades, it has been poorly conceptualised or defined as a discrete phenomenon. This lack of conceptualisation and definition has impeded an in-depth exploration of the phenomenon, its origins and the development of supportive approaches to address caregivers' disconnect with the idea and practice of taking care of themselves and their own needs. However, this study's conceptual rendering of 'The self-care disconnect' offers a new contribution to existing knowledge by offering an analytic lens or way of talking about caregivers' reluctance to consider and take care of themselves and their own needs in caregiving.

'The self-care disconnect', as articulated in this study, is anchored in caregivers maintaining a full focus on the care recipient needs to the exclusion of their own, which has

also been identified across a range of other studies (Dahlborg Lyckhage & Lindahl 2013; Duggleby et al. 2017; Jowsey, Strazdins & Yen 2016). For example, a qualitative study of family caregivers and health professionals in a UK hospice setting identified the way that caregivers apportion full focus on the care recipient:

> Caregivers had a blinkered inability to recognise and respond to their own needs due to their preoccupation with the care needs of the patient and the 'autopilot' approach this engenders (Harrop, Byrne and Nelson 2014, p 6).

One of the underlying factors driving this full and unwavering focus on the care recipients' needs, identified in the findings of the present study, was a perception that to do otherwise would be 'selfish'. This appeared to be founded on a binary or transactional view amongst caregivers that taking time and attention for themselves and their own needs would translate into taking time and attention away from the care recipient. Whilst the palliative care ethos firmly advocates caring for the patient and their family as 'the unit of care', the idea and importance of caring for the carer, alongside the care recipient, has not filtered down into the consciousness of caregivers in this present study or, so it seems, in many others (Nissim et al. 2017).

Findings in this present study also pointed to the influence that cultural messages received more broadly in life about always putting other people first, added to caregivers' reluctance to consider their own needs. Molly, who was caring for her husband with end-stage heart disease, provides the only example of a caregiver in this study holding the view, prior to learning mindfulness, that it is important to take care of herself and her own needs as a caregiver. Molly described a lifetime of being a feminist as the impetus for valuing self-care in caregiving, and this provides some evidence of the importance of receiving positive

messages about self-care and its legitimacy. In the absence of such messages, caregivers were regarded to adopt the position of delayed self-care until after the care recipient had died or alternatively, until crisis prompted the critical need to take care of themselves.

The paradigms of psychology and medicine have largely influenced the framing of self-care amongst caregivers. A small number of studies have explored the impact that dominant, cultural or social messages have on caregivers' view on caring for themselves. Cultural norms that emphasise 'stoicism' and 'self-reliance' in the face of difficulty have been identified (Robinson, Pesut & Bottorff 2012), as well as a sense of familial duty or responsibility to 'care for your own' (Martz & Morse 2017). Few studies, however, have unpacked the social constructions around the end-of-life caregiving role. Carlander et al. (2010) called for greater research in this area after identifying, in a study of ten advanced cancer caregivers, that social ideals and attitudes about caring had a profound influence on caregivers' sense of themselves and their role:

> Caregivers stretched their limits to satisfy the expectations from themselves, the dying person and society…this raises questions about the kinds of ideals that are prevalent in society regarding informal caregiving at home (p 1102).

A study by Fownes Breiddel (2012) exploring the self-care practices among health professionals in a palliative care context identified that positive social and cultural messages within the workplace, about the validity and value of self-care, underscored engagement in and the sustainability of self-care activities.

The 'non-focus' on caregiver needs by others, both family and service providers, was another contributing factor identified in this present study as underlying caregivers' experience of being invisible and not having legitimate grounds for support. This supports

the findings of an increasing body of literature, which has documented caregiver needs being overlooked, particularly by service providers (Hudson & Payne 2011; Lund et al. 2015; Morris & Thomas 2001; Zapart et al. 2007). Several studies have found that embedding assessment of caregiver needs as part of routine care is one way to legitimise the focus on caregiver needs (Aoun et al. 2015a; Ewing & Grande 2013; Harrop, Byrne and Nelson 2014). However, a 2015 report of caregivers in the US found only one in six caregivers reported having been asked what they needed to care for themselves and their needs (National Alliance for Caregiving & AARP 2015). The present study lends support to this finding, with none of the eight caregivers interviewed reporting that they had an assessment of their needs either formally or informally. More disturbingly, for one carer, Ava, her multiple requests for social work services did not eventuate in referral or receipt of support. This study reinforces assertions by Hudson, Remedios & Thomas (2010, p 4) that there is 'a disconnect between what is advocated in policy (that family caregivers are assessed and adequately responded to) and what actually happens in practice'.

Within this present study, health-care providers were regarded as well placed to raise the consciousness of caregivers in terms of the importance of taking care of themselves and their own needs, which resonates strongly with existing literature (Ewing & Grande 2013; Harrop, Byrne and Nelson 2014; Lorenz et al. 2008). Pope et al. (2017) contend that health-care providers work collaboratively with caregivers to develop personal plans for self-care and to enhance wellbeing. Authors such as Robinson, Pesut & Bottorff (2012) and Harding and Higginson (2001) have recommended that self-care is presented to caregivers in terms of the benefit it will offer the care recipient, such as being able to provide and sustain better quality care. They advocate this as the most acceptable way of presenting self-care in a positive light to caregivers. In contrast, the facilitators in the

present study strongly challenged maintaining the 'status quo' in this way, emphasising instead that health providers should actively construct and disseminate a new self-care narrative, one that actively reframes the idea of self-care as selfish and conveys the benefit of caregivers 'caring for themselves' *and* 'caring for others'. These findings point to a new narrative, one that challenges the binary transactional view that taking time and care for themselves means stealing time and care away from their significant other. A more helpful narrative, in the view of the participants in this study, was one that advances nourishment of both caregiver and care recipient needs as 'a unit of care'. It seems incredulous that such a noted phenomenon as caregivers' reluctance to consider and care for themselves and their own needs, with its demonstrated significant adverse effects in terms of disruption to mental and physical health (Duggleby et al. 2017), has not been matched with a significant effort to develop ways to counteract this.

A significant finding in this present study was the way in which MBIs facilitated caregivers to think about and action self-care in the context of caregiving, which was something they had previously resisted. Participants explained that, by learning and using mindfulness, caregivers cultivated a capacity to consider and voice their own needs in a context in which the person for whom they were caring, was ordinarily assumed to have the most significant, if not the only legitimate needs. In doing so, caregivers spoke of finding a way to recalibrate or find a new balance between acknowledging and supporting the care recipients' needs, as well as their own. Caregivers revealed that prior to learning mindfulness this balance of needs was difficult to negotiate: *'I came to a better place, where my needs mattered too'* (Gwen), and '*I realised just because you* [her mother] *are dying, doesn't mean you get everything you ask for'* (Sarah). However, this was often

communicated hesitantly, as if this was something as caregivers they should neither feel, nor voice aloud.

The third overarching process of this model, 'Gaining in a Landscape of Loss: The Value and Benefit of Mindfulness in End-of-Life Caregiving' discusses more fully, the way in which mindfulness catalysed caregiver willingness to consider and take care of themselves and their own needs and further, provided a way to do so. This decision rests on the finding of a strong interrelationship between the benefits of self-care, reconnection with a sense of self and repositioning into brief, but important moments of respite or more grounded spaces.

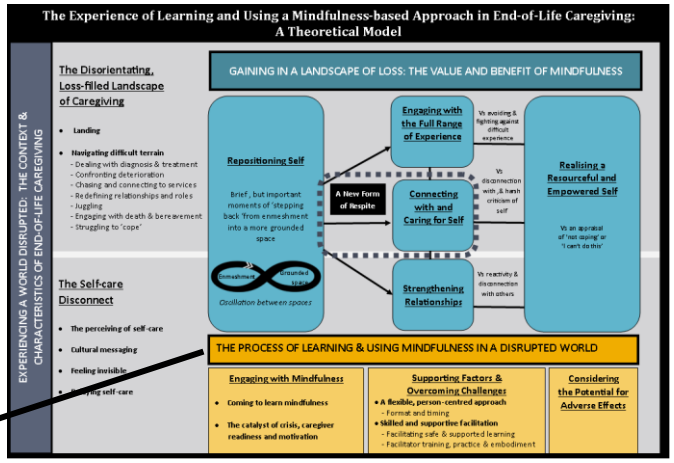
This section of the discussion has detailed the first overarching process, represented on the left-hand side of the theoretical model developed in this study: 'Experiencing a World Disrupted: The Context and Characteristics of Caregiving'. Understanding the context and characteristics of the disrupted world of caregiving was considered, by the caregivers in this study, to be critical to understanding why they engaged with mindfulness and what it offered them. The following section moves to discuss the second overarching process of the developed theoretical model and how this resonates with or challenges existing literature and assumptions.

8.5 Unpacking the Theoretical Model (Process 2)

This section addressed the second overarching process in the theoretical model developed in this study, 'The Process of Learning and Using Mindfulness in a Disrupted World'. As detailed in Chapter Five, findings were represented by three key categories, 'engaging with mindfulness', 'supporting factors and overcoming challenges' and

'considering the potential for adverse effects'. These findings convey how caregivers can be supported to engage with, overcome difficulty and receive benefit from learning and using mindfulness in the complex setting of end-of-life caregiving. This section of the discussion begins by emphasising the value of understanding what it is like to learn and use mindfulness as an informal palliative caregiver. Four critical elements that define this process and which require further consideration in the development and offering of mindfulness-based approaches in this setting are then addressed. These include (1) reconsidering assumptions about timing: caregiver readiness and the catalyst of crisis, (2) rethinking a one-size fits all model, (3) retaining the dharma of mindfulness through skilled and experienced mindfulness facilitation, and (4) mitigatable adverse effects.

The second overarching process of the theoretical model developed in this study: 'The Process of Learning and Using Mindfulness in a Disrupted World 'and its attendant categories, has been lifted from the grounded theory diagram and provided below as Figure 10.



THE PROCESS OF LEARNING & USING MINDFULNESS IN A DISRUPTED WORLD

Engaging with Mindfulness
- Coming to learn mindfulness
- The catalyst of crisis, caregiver readiness and motivation

Supporting Factors & Overcoming Challenges
- A flexible, person-centred approach
  - Format and timing
- Skilled and supportive facilitation
  - Facilitating safe & supported learning
  - Facilitator training, practice & embodiment

Considering the Potential for Adverse Effects

Figure 10: The Second Overarching Process of the Theoretical Model

8.5.1 Understanding the Process of Learning Mindfulness in End-of-Life Caregiving

As discussed in Chapter Three of this thesis, current understanding and guidance are lacking about when to offer mindfulness-based interventions to caregivers, in what way, how much and by whom, as well as understanding potential risks for this population. This present study does not claim to have found the definitive or unequivocal answers to these questions. However, it has purposefully engaged and amplified the voices of those most likely to have insight into the important elements in the construction and offering of such approaches in end-of-life caregiving, but who have been largely neglected as sources of knowledge within the existing literature. These have included informal palliative caregivers who have learnt mindfulness, and those have taught mindfulness in this context. The following key findings offered in this study, whilst uniquely grounded in the lived experience of mindfulness-based approaches in end-of-life caregiving, can only provide preliminary guidance in relation to several issues requiring consideration. Further research is required to specifically explore and test issues of design and implementation of mindfulness-based approaches in the palliative caregiving context with larger samples.

8.5.2 Reconsidering Assumptions about Timing

Study findings prompt a reconsideration in terms of fixed views about the 'best time' to offer mindfulness in this setting. Whilst mindfulness was regarded by the participants in this study as a skill best taught early in life, to cultivate an established mindfulness resource that could be drawn on in more difficult times, there was a strong view that it was possible

for caregivers to learn mindfulness at many different points along the caregiving and bereavement trajectory. Facilitators advocated learning mindfulness earlier in the caregiving trajectory, or post caregiving, to place fewer demands on their time and resources. However, many of the caregivers in this study indicated that reaching a crisis-point was the catalyst for them to seek mindfulness training and that it may well take a sense of being in crisis to cut through the strongly embedded self-care disconnect previously unpacked in this discussion. Existing studies, investigating issues of timing and motivation for informal palliative caregivers to engage in other (non MBIs) supportive interventions have identified similar findings (Lu & Wykle 2007; Pope et al. 2017; Swartz & Keir 2007). For example, a qualitative study used in-depth interviews to explore the respite experience of 10 family dementia caregivers, 80% of whom were female (Strang et al. 1999). The authors found that caregivers' perception of their situation exceeding existing coping strategies and threatening their own health and the sustainability of caregiving was a key factor in their decision to accept respite. In another study, Swartz & Keir (2007) found that elevated levels of stress among 60 family caregivers of people with brain tumours significantly increased caregiver interest in engaging in stress reduction programs.

The findings in the present study significantly challenge the established assumption in the mindfulness-based literature: that mindfulness-based approaches are too difficult and inadvisable to engage with in life periods characterised by high stress (Manocha 2000; Segal, Williams & Teasdale 2018). Strikingly, three of the eight caregivers in this study disclosed having had suicidal ideation at the time of learning mindfulness. The recommended practice across a range of established mindfulness-based interventions would likely have ruled them ineligible to participate in mindfulness training due to their suicidality and level of distress (Dionna & Gonzalez 2009; Hanley et al. 2016; Santorelli 2014). However, all three caregivers

in this study attributed mindfulness with having 'saved their life' which prompts further thought about whose decision it should be in terms of the best time to learn mindfulness in caregiving. Findings in this study strongly convey that caregivers be supported to be self-determining in terms of when it is 'the right time' for them to learn mindfulness. This was not to say, however, that learning mindfulness whilst actively caregiving or experiencing distress was easy. Caregivers clearly articulated tensions between finding the time to learn and practice mindfulness yet finding it highly beneficial when they did. This sense of feeling torn between not finding time for practice yet needing the practice for their self-preservation is a familiar theme in the literature, documented by a range of studies across diverse populations (Morgan, Simpson & Smith et al. 2015; van der Riet et al. 2015). Arguably, this tension and its implications are more pronounced in the context of 'the deficit of time', characteristic of end-of-life caregiving. The way in which caregivers resolved this tension was by 'doing what they can' with the view of engaging in more comprehensive mindfulness training when circumstances permitted, which for two caregivers, occurred after the death of their significant other. This was founded on the view that learning mindfulness is '*a lifelong process*', which opens up the possibility of beginning to learn it at any time, in any capacity, and learning more, if required, over time.

8.5.3 Re-thinking 'A One-Size-Fits-All-Model'

Rather than advancing a 'one-best model', for mindfulness-based approaches in end-of-life caregiving, this study's findings emphasised the need for mindfulness training to be offered in a way that is 'manageable' for caregivers, amidst the commonly shared stressors, demands and deficit of time, characteristic of the caregiving experience. In addition, it is suggested that mindfulness-based approaches be delivered not only at a time, but also in a

format that is acceptable to and considers the unique needs, preferences and circumstances of individual caregivers. This was regarded as critical to facilitating caregiver engagement in the learning of mindfulness, and the experience of benefit. The following section discusses these findings under the sub-headings: (1) a context sensitive approach, tailored to the common challenges of end-of-life caregiving and (2) a person-centred approach, tailored to the individual caregiver.

A Context Sensitive Approach - Tailored to the Common Challenges of End-of-Life Caregiving

The importance of adopting a context sensitive approach which ensures mindfulness training is tailored to the common challenges of caregiving, previously described, was strongly articulated in this study. This was based on the idea that support interventions need to be offered to caregivers in a way that is perceived manageable or feasible for caregiver engagement. This concern has been articulated in the existing mindfulness-based intervention research within the informal palliative care setting (Hoppes et al. 2012; Lengacher et al. 2012; Whitebird et al. 2013), as well as within caregiver intervention research more broadly (Grande et al. 2009; Harding & Higginson 2001). 'Manageable' mindfulness approaches identified in this present study involved a number of different considerations. For example, there was a view that continuing to offer the more traditional 8-week groupmindfulness programs of MBSR and MBCT was valuable, but in addition, less time intensive mindfulness training should be offered. This included approaches that adapted, or lifted-out, components of the more comprehensive programs. For example, from the experience of participants in this study, offering a fewer number and duration of sessions and smaller one-to-one teachings, as opposed to only offering the more time-

intensive, group-based programs, would make mindfulness more manageable in the context of caregiving.

In the present study, the use of technology to assist caregiver engagement with mindfulness-based approaches was identified as beneficial and another way to make learning mindfulness more manageable. The trialled delivery of mindfulness-based approaches through the mediums of telephone or smart phone applications (apps) suggests further research in this area. This is particularly important because this study found a number of older female caregivers in rural areas have used these mediums to learn mindfulness. This may challenge the prevalent assumption that only younger generation caregivers would be willing to use these modalities. Despite the increasing volume and interest in mindfulness-based apps, only a small number of studies have evaluated their effects, pointing to the need for further efficacy research (Mani et al. 2015; Plaza et al. 2013; Van Emmnerik, Berings & Lancee 2018). Evidence in other studies have suggested that delivery of mindfulness programs, either by telephone or online, may support caregivers to overcome access barriers commonly identified in the research literature. These barriers include travel distance and cost (Kubo et al. 2018), lack of available local programs, particularly in rural areas (Springer et al. 2016) and difficulty leaving the care recipient (Kubo et al. 2018; Stjernswärd & Hansson 2017).

Findings of the present study also prompt a reappraisal of 'formal mindfulness practice' requirements in two ways. Firstly, findings suggest a reconsideration of the amount of formal practice required to deliver benefit in end-of-life caregiving and secondly, whether informal mindfulness practice undertaken within everyday life activities may be more important in this setting than longer periods of formal mindfulness practice. For

example, all caregivers reported benefit from learning mindfulness, despite not engaging in as much formal practice as recommended and by practising mindfulness more regularly within the flow of everyday life, as opposed to instituting lengthy periods of formal practice. For two caregivers, mindfulness was only practised in response to difficult situations, indicating that for some, knowing enough to 'use mindfulness' when required, may be sufficient. Similar findings in terms of receipt of benefit from mindfulness, despite lower than prescribed formal mindfulness practice, have been identified in a range of other studies both within the informal palliative caregiving context (Fegg et al. 2013; Kogler et al. 2013b) and more broadly across a range of other populations (Carmody & Baer 2009; van der Riet et al. 2015).

Current understandings of the effective 'dosage' of supportive caregiver interventions generally (Eagar et al. 2007; Rubbens, De Clerck, Swinnen 2017) and MBIs specifically, are mixed. Whilst studies in the MBI literature broadly have found the number and length of mindfulness sessions (Davidson et al. 2003; Huppert & Johnson 2010) and formal mindfulness practice at home (Carmody & Baer 2008; Sephton et al. 2007; Ong, Shapiro & Manber 2009) to be associated with increased benefit (Speca et al. 2000), others have not (Berk et al. 2018; Dobkin & Zhao 2011). Authors such as Carmody and Baer (2009) strongly advocate that where access to mindfulness training is an issue, such is the case for informal palliative caregivers, more flexible and modified mindfulness protocols and programs should be explored. Similarly, the present study suggests that perhaps dosage doesn't have to be as prescriptive as previously considered in the context of end-of-life caregiving. All caregivers reported benefit, despite engaging in different intensity mindfulness-based approaches and not practising as much as prescribed. This supports the

finding of Berk et al. (2018, p 7) in a review of MBI for family dementia caregivers who argued:

> A shorter program or shorter sessions might be just as effective and would make it more accessible for a larger number of people. In particular, time investment could be a major obstacle for caregivers with people with dementia and a shorter program could increase the likelihood of participation.

A Person-centred Approach: Tailored to the Individual Caregiver

Whilst this study identified a strong view among participants of the need for mindfulness-based programs to be offered in a way that is sensitive to the common challenges in caregiving, tailoring to the individual was also considered paramount. Caregivers in the study cautioned against the assumption that they all had the same needs and preferences. Rather, a person-centred approach in offering mindfulness-based approaches to informal palliative caregivers, in recognition of individual diversity, was recommended. This approach would entail offering a range of options for learning mindfulness and allowing caregivers to be self-determining in terms of their preferred format. There was also a concern not to impose a paternalistic or deficit-based view on caregivers' ability to engage with the more intensive and comprehensive mindfulness-based programs. For example, two caregivers in the present study learnt mindfulness in an intensive, group-based format, whilst actively caregiving. One of the caregivers had to travel three hours return to access the program. Both caregivers reported benefit from peer support, validation of needs and normalisation of experience. Mindfulness facilitators also spoke of observing caregivers amidst considerably stressful and intense caregiving experiences, wanting and being able to complete the more comprehensive programs.

A person-centred approach advanced in this study also involved the possibility for tailoring mindfulness teaching and practices regarding caregivers' specific needs such as difficulty sleeping or reactivity. One rural caregiver, Molly, particularly valued having more targeted mindfulness sessions to select from, based on the most difficult aspects of her life.

A person-centred approach significantly challenges both current offerings of mindfulness-based interventions and caregiver support interventions more broadly. For example, whilst the concept of person-centred care is advocated in the palliative care paradigm over a blanket-approach to caregiver support (Grande et al. 2009; Harrop, Byrne & Nelson 2014; Palliative and end of life care Priority Setting Partnership (PeolcPSP) 2015; Robinson, Pesut & Bottorff 2012; Stajduhar et al. 2010b), it has been questioned how well this ethos is translated into practice (Cruz, Marques & Figueiredo 2017; Diffin et al. 2018; Hebert & Shulz 2006; McCorkle & Pasacreta 2001; Ussher et al. 2009). Harding and colleagues (2012a, p 1975) assert:

> Despite widespread agreement for the development of tailored and specific services for informal caregivers in palliative care, such interventions are rare.

While person-centred care is not an alien concept within the field of palliative care, providing this approach in the context of mindfulness-based interventions does significantly challenge current understandings and ways of offering mindfulness training. The format of a structured, intensive, eight-to-nine-week, group mindfulness course has been the most common way of teaching mindfulness in western health and social care settings, irrespective of different contexts and client populations, and the most frequently researched (Keng, Smoski & Robins 2011; Khoury et al. 2013). It is also the most evaluated type of MBI in the literature (Jaffray et al. 2016) and the one with which health-care sectors

and funding bodies appear most comfortable, due to its structured approach that can be delivered efficiently to multiple individuals at one time (Zabat-Zinn 2003). However, this present study suggests that within the intense and time-sensitive context of end-of-life caregiving this blanket-approach requires rethinking. Instead caregivers should be offered a range of approaches and be empowered to decide what format will work best for them. Findings from this study point to caregivers receiving benefit from engaging in a wide range of mindfulness-based approaches such as one-on-one sessions, group programs or by a mobile phone app, of varied durations, and engaging in different amounts of home mindfulness practice. Adopting a more flexible and curious approach to what might work best in this setting may be a way forward. However, working with the implications that this non-standardised approach may have for securing program funding will be required (Berk et al. 2018). This study's findings add to calls in the current palliative caregiving literature more broadly for greater focus on flexible, person-centred caregiver support interventions (Applebaum et al. 2014; Henwood, Larkin & Milne 2017; McCorkle & Pasacreta 2001; Thomas et al. 2017; Ussher et al. 2009).

8.5.4 Retaining the Dharma of Mindfulness: Skilled and Experienced Facilitation

Another central feature of the second overarching process of the theoretical model, 'The process of learning and using mindfulness in a disrupted world', is the importance of skilled and supportive mindfulness facilitators to retain the Dharma of mindfulness. As explained in Chapter Two, Dharma often refers to the essence or truth of Buddhist teachings, including mindfulness. It is used here to refer to the essence or comprehensive knowledge, skills, practice and lived-experience of mindfulness. The need for mindfulness to be taught by a skilled, supportive and experienced mindfulness facilitator was regarded to

underscore caregiver engagement in learning mindfulness and the experience of benefit in the setting of end-of-life caregiving. This was also considered essential in terms of mitigating potential adverse effects. This section discusses these findings in relation to current understanding in the two literatures of mindfulness-based interventions and informal palliative caregiving, as they have different implications in each domain.

Study findings emphasised that whilst there was value in offering adapted, more flexible, person-centred mindfulness-based approaches, there remained a need to ensure that they continued to be taught by skilled and experienced mindfulness facilitators. This was regarded as essential to retaining the Dharma of mindfulness or ensuring the essence of mindfulness was not lost in the process of lifting out and teaching parts of what are conceptualised as holistic and comprehensive programs like MBSR and MBCT.

Skilled and experienced mindfulness facilitation was regarded in this study to rest on: (1) facilitators having undergone training in mindfulness themselves, (2) having an established and ongoing self-practice of mindfulness to know, from the emic perspective, the process and challenges inherent in learning and using mindfulness over time, and (3) embodying a mindfulness approach in their engagement with caregivers. These foundations of mindfulness teaching are similarly recommended across the mindfulness literature (Crane & Hecht 2018; Evans et al. 2015), with skilled, experienced mindfulness facilitation regarded as the most critical factor underpinning the effectiveness and fidelity of mindfulness-based approaches (Baer 2003; Crane & Reid 2016; Kabat-Zinn 2003; Ledesma & Kumano 2009; Speca et al. 2006).

However, within the field of palliative caregiving these specific requirements for teaching mindfulness to caregivers appear to be less understood and accepted. For

example, the sustainable offering of palliative caregiver support interventions in general have been found to rest heavily on the capacity of staff within palliative organisations being able to provide them without additional resources (Hudson, Aranda & Kristjanson 2004; Ellington et al. 2013; Given, Given & Sherwood 2012). Several mindfulness facilitators in this study pointed to the growing, unhelpful assumption that health or social care organisations can have existing staff teach mindfulness to caregivers in the absence of the above-mentioned foundations for the effective teaching of mindfulness. As one facilitator stated:

> *If we keep training people in the ways we have - organisations expect to be able to send their staff out to do an eight-week training course in mindfulness and they think okay, you've got mindfulness, now you can teach your clients. It's exceptionally rarely the case* (F 4).

It is reasonable to question participant bias in relation to these claims. It could be expected that the mindfulness facilitators who participated in this study may inflate the importance of their perceived expertise and knowledge base. Whilst this cannot be entirely disproved, this study's findings concur with existing mindfulness literature that emphasises the range of knowledge and experience advocated by the facilitators in this study (Crane & Hecht 2018). In addition, the caregiver participants in this study also emphasised the value of having been taught mindfulness by someone who had an established knowledge of and personal practice in mindfulness and who were able to help them answer questions and overcome challenges, from having faced similar difficulties themselves.

Additional to the foundational training and experience in mindfulness, this study also identified group work skills and a range of clinical skills as important for teaching mindfulness in an effective, supportive way in the intense setting of end-of-life caregiving.

These included: (1) skilfulness in developing and maintaining trusted relationships with caregivers who were regarded to be in a very stressful, vulnerable period of their lives, (2) attuned assessment skills to monitor and adapt mindfulness teaching in relation to individual caregivers' mental health needs and (3) management of the potential for mindfulness to resurface past trauma.

8.5.5 Mitigatable Adverse Effects

The final critical finding in the second overarching process of the theoretical model to be addressed in this section, relates to the consideration of potential adverse effects from offering mindfulness-based approaches to informal palliative caregivers. To date there has been limited qualitative exploration of the potential for adverse effects of learning mindfulness in end-of-life caregiving (Jaffray et al. 2016) or indeed in any context (Davidson & Dahl 2018; Dobkin & Zhao 2011; Farias & Wikholm 2016; Van Dam et al. 2018a). This is a significant gap in the literature which may mean that a skewed view towards the positive effects of mindfulness has been obtained. This may be by virtue of research participants with positive experiences having engaged in research. In addition, whilst studies routinely report finding no evidence of adverse effects from learning mindfulness, research has not specifically sought to explore this. In contrast, this research did ask specific questions about the experience or perceived potential for adverse effects. The genesis of this question was anchored in a commitment of not wanting to create additional burden or adverse experiences for a population that already endure enough challenges.

This study, however, found that no caregivers experienced adverse effects, despite three caregivers disclosing having been suicidal when commencing mindfulness training. In addition, none of the caregivers perceived potential risks for other caregivers learning

mindfulness. It must be considered that this finding might reflect that only caregivers with positive experiences of mindfulness elected to be part of this study and that a different sample might yield a different experience of and appraisal of risk. The finding of no risk of adverse effect or harm, in this study, however, is consistent with other mindfulness intervention studies with informal palliative caregivers as reviewed in Chapter Three (Franco, Sola & Justo 2010; Hoppes et al. 2012; Kogler et al. 2013b; Oken et al. 2010; Stöckle et al. 2016; Whitebird et al. 2013).

Facilitators, with significant prompting, identified a limited number of potential adverse effects for caregivers with existing mental health illness, by referencing their experiences more broadly with teaching mindfulness to other populations. Potential adverse effects included: experiencing a sense of failure, increased depression, trauma activation and altered states of consciousness. Participants interpreting a sense of failure to learn and use mindfulness 'properly' is cited in the existing literature (Banerjee, Cavanagh & Strauss 2017; Stjernswärd & Hansson 2018). However, skilled, experienced mindfulness facilitation was perceived to mitigate these potential adverse effects, a finding which resonates with the existing literature:

> The skill of the instructor in dealing with such eventualities (challenges in learning mindfulness) may be important in determining whether they become valuable learning opportunities or alternatively adverse effects (Melbourne Academic Mindfulness Interest Group 2006, p 290).

These findings of limited potential for adverse effects in the presence of skilled and experienced mindfulness offer some level of confidence in terms of mindfulness not posing any further risk to an already vulnerable, yet arguably, resilient population. Having said that, with increasing exposure it is important that mindfulness-based interventions are not simply

implemented in the informal palliative caregiving setting without carefully understanding the context and possible implications, one of which is the imperative for skilled and experienced mindfulness facilitation. It remains important to continue to seek a balanced view in terms of both potential benefit and adverse experiences, especially as practice and research evolves in this field.

8.6 Unpacking the Theoretical Model (Process 3)

This section addresses the third overarching process of the theoretical model developed in this study. It comprises the overarching process, 'Gaining in a Landscape of Loss: The Value and Benefit of Mindfulness in End-of-Life Caregiving'. A conceptual account of the experience of mindfulness in end-of-life caregiving, grounded in the lived experience of caregivers and mindfulness facilitators, has been previously absent in the research literature.

This section is structured in three main parts, which reflect the most critical findings. Firstly, owing to the strong sense of movement which permeated all study findings pertaining to the benefits of mindfulness in end-of-life caregiving, the five key categories of benefit will be spoken about through the concept of 'positional shifts'. This concept will help explain the changed way in which caregivers came to relate to their experience, self and others. Secondly the idea of mindfulness as a new form of respite will be presented. This involves caregivers obtaining restorative moments of reprieve and rest, without removal, will be presented. Finally, considering the diverse range of benefits identified in this study, approaches to measuring the effects of mindfulness-based interventions in end-of-life caregiving will be discussed.

The third overarching process of the theoretical model developed in this study, has been lifted from the grounded theory diagram and is provided here in Figure 11.

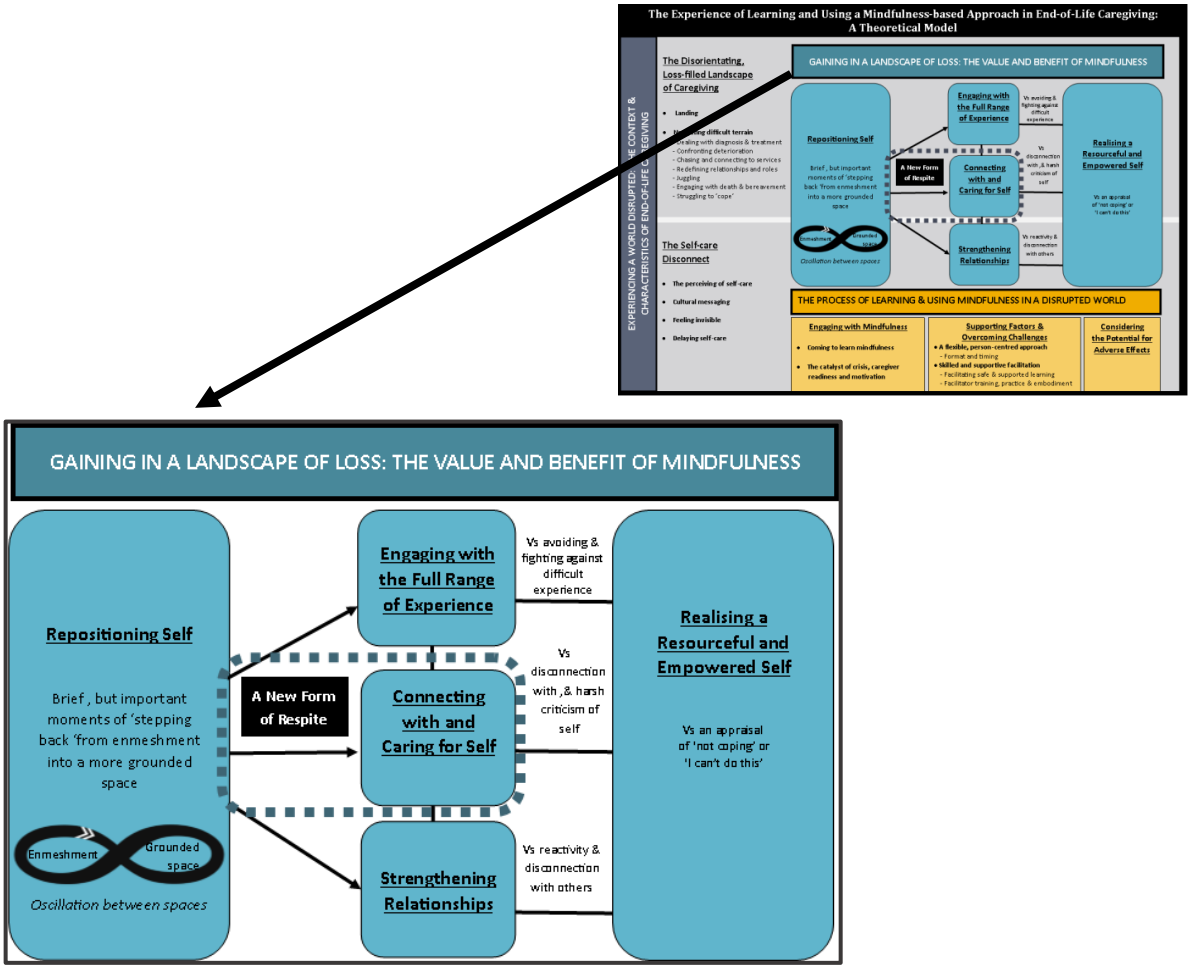


Figure 11: The Third Overarching Process of the Theoretical Model

8.6.1 Positional Shifts

Permeating all key categories of benefit and value from learning and using a mindfulness-based approach in end-of-life caregiving, identified in this study, was the idea of a significant movement or process of change in the way that caregivers engaged with their experience, themselves and others. In describing these significant movements, participants used words such as 'compared to', 'as opposed to', and 'in contrast to', to emphasise how mindfulness offered something that was either previously absent or very

different from what was frequently experienced in caregiving. This section moves to conceptualise this process of movement, as one of 'positional shifts'. Each of the five categories of benefit identified in this study will be explored through this analytical lens of 'positional shifts', conceptualised as empowered movements enabled by mindfulness. Further, the ways in which these shifts ultimately underscore the sense of being more able to 'cope' with the intense challenges in caregiving are discussed. Figure 12 visually illustrates how the key benefits identified in this study can be understood in terms of 'positional shifts'.

Positional Shifts from Learning and Using Mindfulness-based Approaches in End-of-Life Caregiving

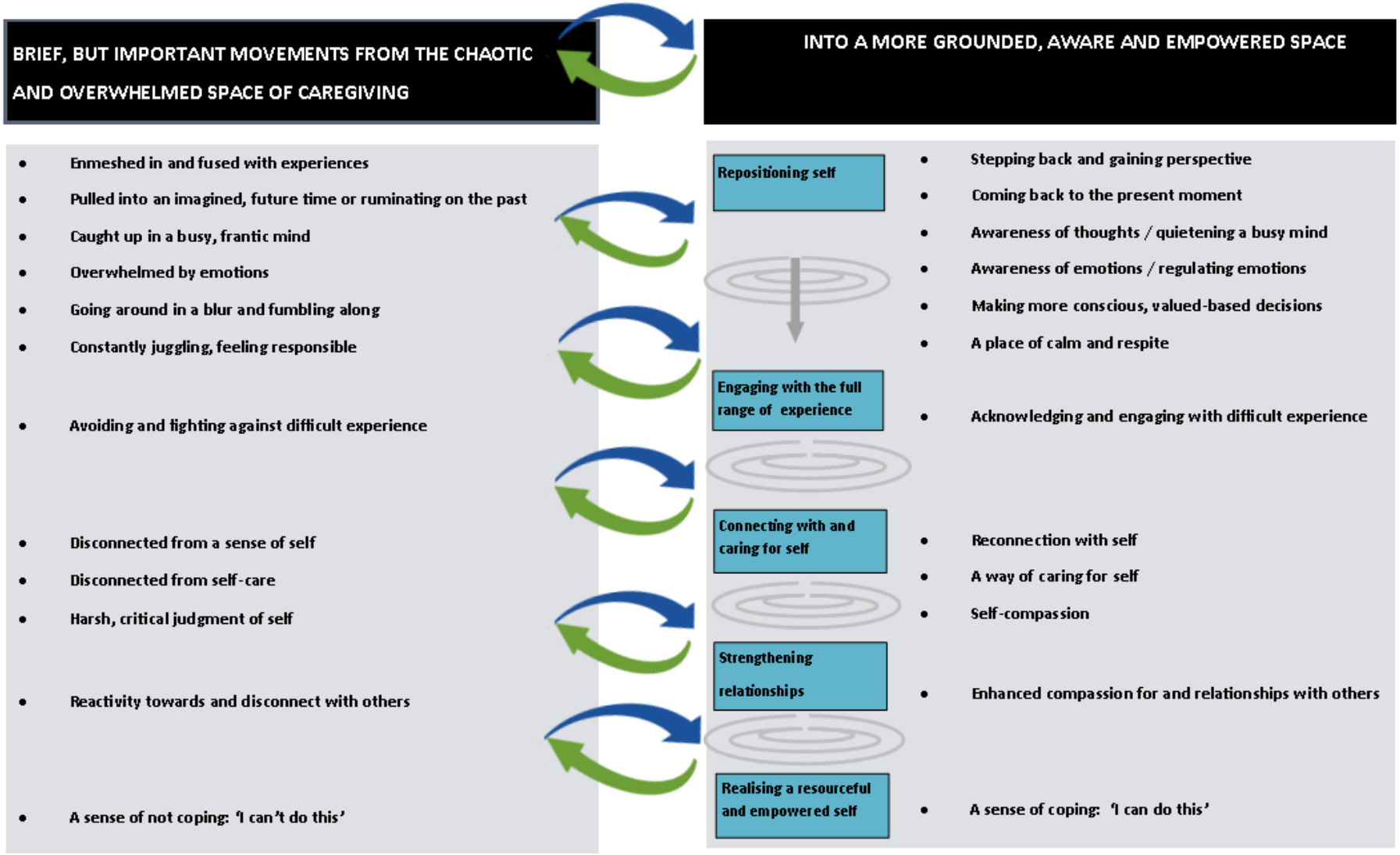


Figure 12: Positional Shifts from Learning and Using Mindfulness in End-of-Life Caregiving

Positional Shift One: From Enmeshment and Overwhelm to a More Grounded Space

The first key benefit identified in this study was that mindfulness enabled caregivers, brief, but vitally important intervals of repositioning themselves or 'stepping back' from being enmeshed in and defined by their experiences, thoughts and feelings. This can be regarded as the first positional shift from which other positive movements and benefits derive. This finding of 'repositioning self' resonates strongly with Shapiro's (2006) model of 're-perceiving', detailed in Chapter Two. Shapiro's concept of re-perceiving details the way in which mindfulness enables people 'to stand back from' and take a different perspective on their experience as opposed to being 'immersed in the drama of it', thereby enabling greater awareness, decreased reactivity and enhanced cognitive and behavioural flexibility (Shapiro 2006, p 377). Similarly, this present study's finding of caregivers repositioning themselves regarding their experience, concurs with the qualitative meta-synthesis of Malpass et al. (2012) who reviewed studies of patients with mental and physical health issues and Morgan, Simpson & Smith (2015) who synthesised the results of qualitative MBI studies of health-care providers. Both studies reported strikingly similar descriptors of 'standing back from', 'stepping back from', and 'dis-identification' from experience.

The present study also strongly supports the 'decentering' and related constructs in the existing mindfulness literature, proposed by many authors as key mechanisms of action (Bernstein et al. 2015; Fresco et al. 2007; Gu et al. 2015; Hoge et al. 2015; Segal, Williams & Teasdale 2018; Shoham et al. 2017; Teasdale et al. 2002). Decentering has been conceptualised as a metacognitive capacity to 'shift experiential perspective from *within* one's subjective experience, *onto* that experience' (Bernstein et al. 2015, p 599). Adopting this observant perspective as opposed to becoming fused with one's thoughts and feelings,

is regarded to transform or 'change the very nature of those experiences' (Safran & Segal 1990, p 117) and to underscore enhanced mental health (Bieling et al. 2012; Gu, et al. 2015; Shapiro et al. 2006).

Further to describing a process of mindfulness enabling caregivers to reposition themselves in relation to their experience, the theoretical model developed in this present study, detailed the qualities and characteristics of the space into which caregivers reposition. This was depicted vividly by the participants in this study as a more grounded, restful and present moment space. This was starkly contrasted with the fraught and busy space more commonly experienced in caregiving, marked by the constant juggling of roles and responsibilities and being pulled into an imagined future. Positive descriptions of mindfulness providing moments of peace, ease, stillness and increased presence have been reported in other mixed method studies of MBIs for informal palliative caregivers (Hoppes et al. 2012; Marconi et al. 2016; Stöckle et al. 2016; van den Hurk et al. 2015). The grounded theory approach used in the present study, however, provided a more nuanced insight into what it meant to be more calm, still and present. It did so by contextualising this experience within rapidly diminishing time, expressed by participants as a striking paradox: that whilst learning mindfulness takes time, it also has the effect of giving back time.

The findings in this study identified that this repositioned space, enabled by mindfulness, also supported greater caregiver awareness of the content and effects of their thoughts and feelings, along with the chance to regulate emotions and steady racing thoughts. This was contrasted with the more common experience of feeling 'dragged along' by a frantic mind and overwhelmed by emotions. These benefits of increased awareness and self-regulation have been documented both in the qualitative MBI literature broadly

(Hoge et al. 2015; Malpass et al. 2012; Shapiro et al. 2006; Wyatt, Harper & Weatherhead 2014) and specifically for informal palliative caregivers (Kogler et al. 2013; Marconi et al. 2016; Stöckle et al. 2016; van den Hurk et al. 2015).

Increased awareness is regarded as a key mechanism of change in many conceptual models of MBIs across different populations (Segal et al. 2018). Caregivers gaining an increased awareness and ability to '*engage with the reality of their situation'*, was also identified in the present study as a beneficial characteristic of this new repositioned space. Acknowledging or 'coming to terms' with the reality of a palliative diagnosis and the role of end-of-life caregiving has been identified in other studies as critical in caregiver adjustment to the multiple challenges and life disruptions resulting from palliative caregiving (Duggleby et al. 2010; Duggleby et al. 2017) and to caregiver willingness to access services (Hawley 2017).

In the present study, increased awareness of the reality of the situation facilitated caregivers to make more conscious valued-based decisions to realise the quality of the moment, as opposed to 'going around in a blur' and 'fumbling along'. This finding corresponds with the concept of 'valued-living' or 'valued-based action', which describes the degree to which people behave in accordance with what they value. Valued-based action is regarded as a key mechanism of therapeutic change in acceptance and commitment therapy (ACT), a mindfulness-informed approach, (Hayes & Wilson 1994). It has been identified as a reported benefit in other mindfulness studies across different populations (Christie, Atkins & Donald 2017; Monteiro, Musten & Leth-Steensen 2018; Shapiro 2006) and in two studies for informal palliative caregivers, specifically (Davis et al. 2017; van den Hurk et al. 2015). For example, in a MBSR study of 19 lung cancer patients and their

caregivers, one of the six processes of benefit were the enhanced ability to consider and consciously change behaviour in line with what was valued (van den Hurk et al. 2015). The present study suggests that this benefit of mindfulness, being more aware and making more conscious decisions, was particularly valued in end-of-life caregiving, where time is precious, or as one participant stated, '*No moment is ever repeated and knowing that fully*' (F 3).

'Repositioning of self', beyond being the first category of benefit, was spoken about as a meta-process, which had a ripple effect of creating subsequent positive shifts or re-positionings across a range of other domains. Specifically, change occurred in terms of how caregivers engaged with difficulty, how they connected with and cared for themselves and how they connected with others. The finding of a meta-process enabling other benefits, resonates with findings in a range of existing MBI studies (Shapiro et al. 2006; Malpass et al. 2012, van den Hurk et al. 2015), reflective perhaps of the holistic and interconnected nature of mindfulness itself.

Positional Shift Two: From Avoiding and Fighting Against, to Engaging with Difficult Experience

Taking further the idea of 'repositioning self' as a meta-process that catalyses other beneficial movements in the process of learning mindfulness, 'engaging with the full range of experience', as the second category of benefit identified in the theoretical model, can be considered a subsequent positional shift. Specifically, rather than avoiding difficult experience for fear of 'falling apart', which was a commonly reported coping strategy prior to learning mindfulness, caregivers came to trust that they had the fortitude to acknowledge and engage with difficult experiences. These findings reflect the results of two mixed method studies of MBIs for informal palliative caregivers (Kogler et al. 2013; Stöckle

et al. 2016), which identified the ability to 'face difficulty' as a key theme of benefit from learning mindfulness in end-of-life caregiving. Qualitative studies of mindfulness-based interventions in other populations have identified similar benefits, framed as 'exposure', 'turning towards difficult experience' (Shapiro et al. 2006), 'facing the difficulty' (Malpass et al. 2012) and 'learning to tolerate difficulty' (Wyatt, Harper & Weatherhead 2014). The literature has explained avoidance as a problematic disengaging from difficult or stressful events or:

> An unwillingness to remain in contact with unwanted private events (i.e, thoughts, feelings, sensations and memories), which becomes problematic when it is rigidly and pervasively applied to the extent that it impinges on the pursuit of what is important and meaningful in one's life (Davis 2017, p 2).

In the context of end-of-life caregiving, avoiding difficult or uncomfortable experiences has obvious implications for connection with, and being able to engage fully in what little time remains with the person for whom they are caring. Experiential avoidance of difficult experience has been associated with psychological distress and prolonged grief in bereaved populations (Boelen, van den Bout & van den Hout et al. 2010; Davis, Deane & Lyons 2016). In contrast, the reduced use of avoidance-based coping styles or the adoption of an engagement response that is 'orientated towards the stressor and one's reaction to it' (Cousin & Crane 2015, p 435) has been proposed as a key mechanism underlying therapeutic change in MBIs (Baer, Smith & Allen 2004; Berking et al. 2009; Davis, Dean & Lyons 2015; Hayes, Strosahl & Wilson 2011; Weinstein, Brown & Ryan 2009).

Acknowledging and learning to 'sit with' difficulty was additionally found, in this study, to suspend an exhaustive, combative stance of fighting against difficult experience or

the struggle for things to be different. Whilst experienced as a relief by caregivers, it was clearly not easy for them to shift from their more familiar stance of fighting against difficult experience, to one of acknowledging and accepting unwanted experience. Several reasons were advanced for this. Firstly, it was such a radically different approach to the care paradigm in the palliative setting, in which most caregiver interventions are focused on removal or distraction from difficulty. Additionally, the notion of acceptance in the palliative care discourse is often conceptualised by caregivers and patients alike, as an act of 'giving up' (Foxwell & Scott 2011) or inviting death closer. Harding and Higginson (2001) have advocated not introducing interventions that challenge existing coping styles, with a view that it could be detrimental to coping and inhibit caregiver uptake of support interventions. However, this present study challenges the prevalent coping style of avoidance and suggests that the starkly different approach of allowing engagement, enables a more holistic experience. For example, a number of participants voiced that the cost of turning away from or fighting against difficult experience was a subsequent turning away from positive experiences that co-exist with those darker moments. An acquired sense of mastery or ability to manage difficult experiences without being '*swallowed whole'* (Ava) was also highly valued. In light of studies, such as Merluzzi et al. (2011), who found that end-of-life caregivers report poor self-efficacy in terms of managing emotionally painful experiences and interactions, the findings of this study show that mindfulness-based approaches might offer a way to increase caregivers' competence to engage with these difficult aspects of experience. Further this, study supports the view of Merluzzi and colleagues (2011, p 23) who strongly advocate that:

> Self-efficacy for managing these difficult experiences (dealing with difficult interactions and emotions, including talking about death and dying, dealing with

> negative feelings from the person for whom they are giving care, being able to express negative feelings and dealing with criticism) …should be an essential aspect of caregiver training.

Positional Shift Three: From Self-Criticism and Disconnection to Care and Connection with Self

The concept of 'positional shifts' or significant movements in how caregivers came to relate to themselves, was also evidenced in the third finding of benefit in the present study, 'connecting with and caring for self'. This finding articulated the way in which mindfulness enabled caregivers to move from a place of a disconnection with a sense of self, harsh self-judgement, and a strong résistance to caring for themselves, prior to learning mindfulness, to experiencing an enhanced sense of self-identity separate from their caregiving role, having increased self-compassion and caring for themselves.

The 'positional shift' or significant movement in how caregivers came to relate to themselves, after learning mindfulness, is particularly profound. It is profound considering the dissolving or lost sense of self, widely documented in the informal palliative caregiver literature (Dahlborg Lyckhage & Lindahl 2013; Funk et al. 2010; Harding & Higginson 2001; Henwood, Larkin & Milnes 2017; Kristjanson et al. 1996; Molyneaux et al. 2011; O'Connor 2007; Ray & Street 2007; Ugalde 2011). For example, in a qualitative study of ten family caregivers 6-12 months post the death of a family member to advanced cancer, Carlander et al. (2010) identified a core theme of 'the modified self', reflective of how caregiving and its challenges, alter caregivers' self-image. Harding and Higginson (2001) identified 'an ambivalent self' and Ugalde (2011), 'a changed self', brought about by caregiving.

Whilst the patient chronic illness literature has explored the concept of supporting 'personhood' or sense of an enduring self-identity in the face of radical disruptions wrought by illness (Kabel & Roberts 2003; Lawton 2002), less attention has been paid to exploring the experience of personhood in end-of-life caregiving and what helps to sustain a sense of self in such a demanding context. A sense of personhood as a caregiver seems to be a critical construct for further exploration. For example, in a grounded theory study of older Canadian caregivers of family members with advanced cancer, maintaining a sense of personhood underscored the process of 'redefining normal', as they adjusted to the transitions and disruptions in end-of-life caregiving (Duggleby et al. 2010). The informal palliative caregiver respite literature has also touched on the importance of caregivers having moments of stepping outside of their caregiver identity (Ashworth & Baker 2000; Strang et al. 1999; Upton & Reed 2005) and the opportunity to 'connect with their other selves' (de la Cuesta-Benjumea 2011, p 1797) to enable a restorative break from caregiving. However, the experience of personhood as a caregiver and its relative importance has not been explored in-depth.

In this study, the finding of mindfulness enabling enhanced connection with a sense of self, resonates with findings of three qualitative meta-syntheses of MBIs for other populations. These included MBIs for patients with mental and physical difficulties (Malpass et al. 2012; Wyatt, Harper & Weatherhead 2014) and health professionals (Morgan, Simpson & Smith 2015). However, as none of the existing MBI studies for informal palliative caregivers reviewed in this thesis, found evidence of a changed sense of self-connection due to learning mindfulness, this present study offers something additional to the caregiving literature. Significantly, a number of female caregivers in this study identified that mindfulness enabled them to experience a sense of self for the first time in their lives

(Gwen, Lorna, Ava, Laura): *'I never knew there was such a thing as a self to be taken care of'* (Lorna, 87-years of age). This speaks to the way in which the benefits of enhanced sense of self-connection, permeated not only the caregiving experience but how caregivers experienced themselves in life more broadly.

Positional shifts were also noted regarding how caregivers moved from a place of harsh, critical self-judgement, to one of increased self-compassion. This finding has been identified in a limited number of other MBI studies for informal palliative caregivers, with the concept of increased self-compassion commonly expressed as 'enhanced acceptance of self' (Hoppes et al. 2012; Marconi et al. 2016; van den Hurk et al. 2015). Evidence in the broader MBI literature for positive effects on self-compassion is more established (Burton et al. 2017; Campos et al. 2016; Rodríguez-Carvajal et al. 2016; van Dam et al. 2011). Increased compassion has been proposed in the mindfulness-based literature to be associated with lower levels of psychological distress (Shellekens et al. 2017), enhanced mental health and wellbeing (Birnie, Speca & Carlson 2010b) and as a protective mechanism against anxiety (Berk et al. 2018; Neff, Kirkpatrick & Rude 2007). Learning to be increasingly compassionate towards oneself as a caregiver is a significant and important outcome for further research, particularly considering the high level of caregiver self- criticism identified in this study.

The other significant positional shift identified in this present study was associated with how caregivers came to relate to themselves after learning mindfulness. In this striking finding there was a positive caregiver movement from a complete disconnect with the idea and practice of taking care of themselves, towards considering and attending to their own needs. Whilst often, only realised in small or brief moments, these mindful self-care moments were communicated as highly valued, as the only moments in which caregivers

could rest and take care of themselves and attend to their inner life of thoughts and feelings. This finding is significant, for whilst caregivers' resistance towards taking care of themselves and their own needs in the context of end-of-life caregiving has long been documented in the existing literature (Dahlborg Lyckhage & Lindahl 2013; Harding, et al. 2012a, Harrop, Byrne & Nelson 2014; Duggleby et al. 2017; Funk et al. 2010; Ugalde 2011), understanding how to address this pervasive phenomenon is lacking.

Interventions that promote the importance of and enable caregivers to engage in self-care within the domains of physical, emotional, social, leisure and spiritual wellbeing, are noticeably absent in the informal palliative caregiver literature (Pope et al. 2017). Most of the evaluated caregiver interventions have focused on increasing caregivers' capacity and preparedness to care for the care recipient, as opposed to enhancing knowledge and ability to care for themselves. It is perhaps not surprising that caregivers often report a lack of confidence in their ability to institute practices of self-care whilst caregiving. For example, Merluzzi et al. (2011) found that caregivers rated their self-efficacy, in terms of ability to care for themselves and manage difficult intrapsychic and interpersonal interactions significantly lower than their sense of self-efficacy to provide care for the care recipient.

Authors such as Vachon (1999) and Pope et al. (2017), argue that limited attention to self-care as a protective factor against caregiver burden and burnout and other adverse mental health outcomes, has been a significant oversight in the informal palliative caregiving literature. This is underscored, perhaps, by the prevailing disease and burden-focused paradigm underpinning intervention development and evaluation in caregiver research. Dionne-Odom et al. (2017a, p 2443) strongly argues for a shift away from the disease and burden-focused paradigm to one that focuses on health and wellness,

'Caregivers who take time to care for themselves may be better able to tolerate the stressors that accompany supporting someone with serious life limiting illness'

The findings in the present study, in accordance with van den Hurk et al. (2015), suggest that learning and using a mindfulness-based approach offers caregivers a way to acknowledge and work with their resistance to self-care, conceptualised in this study as 'The self-care disconnect'. Further, mindfulness provides caregivers with an empowering way to operationalise self-care, by combining 'contemplative traditions and stress management' (McGarrrigle & Walsh 2011, p 214) in a way that enables them to care for themselves, whilst also caring for others.

Positional Shift Four: From Disconnection with Others to Strengthened Relationships

The fourth major positional shift identified in this study concerned the changed way caregivers came to relate to the person for whom they were caring. Specifically, there was an enhanced quality of connection and increased compassion and tolerance, from a place, prior to learning mindfulness, of retreating from or being reactive towards the care recipient and their behaviour. Poignantly, for two caregivers in this study (Ava and Lorna) learning and using mindfulness in end-of-life caregiving, enabled them to come back from a place of complete disconnection from their husbands Ava verbalised as, '*a dreadful, guilt-filled place to be'*. Only two of the twenty-one MBI studies for informal palliative caregivers, reviewed in Chapter Three of this thesis, reported enhanced connection between caregivers and the care recipient as a result of learning and using mindfulness in end-of-life caregiving. For example, improved relationships were identified as one of eight key resources gained through the process of learning mindfulness in a group MBSR program for ALS patients and

caregiver dyads, identified in an ongoing RCT using grounded theory analysis of qualitative interviews (Marconi et al. 2016).

The finding, in the present study, that mindfulness enhanced connection with the care recipient strongly resonates with an increasing body of evidence in the broader caregiver research literature (Hou et al. 2014; Minor et al. 2006; Singh et al.2004). A meta-synthesis by Morgan, Simpson & Smith (2015) of 14 studies of MBSR or MBCT for 254 health-care providers identified changed relationship to experience in the interpersonal domain as a key theme. The changed way of connecting with others was described as involving enhanced empathetic interactions and gaining an increased sense of shared humanity. In this study, the significance of mindfulness enabling enhanced relationships is underscored by the fact that time is of the essence. Paradoxically, whilst learning and practising mindfulness in end-of-life caregiving takes time, it gives back in terms of quality of connection, thereby changing one's experience of time.

Within the existing literature, there are calls for greater focus on supporting the caregiver and care recipient to maintain connection and communication in their relationship (Duggleby et al. 2010; Martin, Olano-lizarraga & Saracíbar-razquin 2016). This is in response to the well-established understanding of the myriad of disruptions to roles and relationships, characteristic of end-of-life caregiving (Martin, Olano-lizarraga & Saracíbar-razquin 2016; McConigley et al. 2010; Ray & Street 2007). Mindfulness may offer one way of offering benefit in regard to the interpersonal domain by supporting enhanced connection, quality of time, compassion and reduced reactivity.

Positional Shift Five: From feeling 'I can't do this', to a sense of 'I can do this'

The way in which mindfulness enabled caregivers to gain a sense of themselves as resourceful and empowered, from previously feeling largely overwhelmed and disempowered, constituted the final and perhaps one of the most powerful positional shifts identified in this study. All eight caregivers spoke of this increased sense of resourcefulness using the words 'better able to cope' with the demands of caregiving, from a previously occupied space of feeling as if they couldn't 'cope'. Facilitators, whilst observing the same effect, expressed this by using different, more academic language such as 'increased personal agency' or 'empowerment', but again this was contrasted with an observation of limited agency prior to learning mindfulness. Participants were very clear that the difficulties and pain of the caregiving landscape were not altered through learning mindfulness, but what did change, was how caregivers came to relate to themselves, which subsequently shifted how they related to their experience. This ultimately led to caregivers feeling better able to cope with what previously felt like an un-cope-able situation.

Caregivers' changed appraisal of themselves as resourceful, was spoken about as the quintessential value of mindfulness, underscored by the four benefits and positional shifts, previously discussed: repositioning self, fuller engagement with experience, connecting with and caring for self and enhanced connection with others. This acquired sense of self-belief or ability to cope with the demands of caregiving was experienced as having a 'huge', transformational and profound effect on the caregiving experience. The magnitude of this benefit was largely unexpected by caregivers and not easily understood in terms of how mindfulness produced these benefits. Molly described it as '*so simple, but so powerful'*. The participants in this study also spoke of how this increased sense of resourcefulness, afforded

by mindfulness, was self-sustaining beyond their facilitators' initial teaching of it. For example, the cultivation of an enduring inner strength was explained to extend beyond caregiving into other facets of their lives such as work, family and bereavement. More importantly, this was not dependent on the ongoing expertise of others.

Empowered shifts in how people relate to themselves through learning mindfulness have been identified in MBI studies for other populations. This finding has been expressed by processes such as 'a changed way of relating to self' in a review of MBI for health professionals (Morgan, Simpson & Smith 2015). In two meta-syntheses of MBIs for patients with mental health issues empowered shifts were identified as the 'renegotiation of relationships with their inner selves' (Wyatt, Harper & Weatherhead 2014) and a 'change in the way in which they experience themselves' (Malpass et al. 2012). The concept of 'reappraisal' of one's self and capacity to encounter difficult experiences are also features in Shapiro et al. (2006) MBI model of 'reperceiving', previously discussed. It is also embedded in several conceptual models (Folkman 1997; Lazarus & Folkman 1984; Perlin et al. 1990) and identified as a mechanism of therapeutic change in the context of different informal palliative care interventions (Hudson 2003a). Enhanced sense of personal agency and personal growth through adversity has been associated with coping and finding meaning in caregiving (Merluzzi et al. 2011; Wong & Ussher 2009). From a strengths-based perspective, supporting caregivers to recognise and build on their innate resources is fundamental to shifting the biomedical, deficit-based approach common in health, which is heavily focused on screening for problems and risk, towards a more empowering approach. It is interesting to note that whilst positive effects have been associated with a sense of personal agency, or internal locus of control, many of the conceptual models seeking to identify and describe

moderators to stress, focus more on access to external resources, as opposed to cultivating connection to an internal resourcefulness.

The concept of self-efficacy is also relevant here. In more recent years, 'self-efficacy', defined broadly as 'one's self-assessment to succeed at any given task' (Ugalde 2011 p 49), has been gaining increased attention in the caregiving literature as a protective mechanism against adverse mental health effects of caregiving. High levels of self-efficacy have been associated with reduced psychological distress, negative mood and caregiver burden (Keefe et al. 2003; Merluzzi et al. 2011; van den Heuvel et al. 2011) and increased quality of life in informal palliative caregivers (Duggleby et al. 2017; 2013; 2014). Self-efficacy measures would appear to be indicated in terms of capturing the effects of MBIs on caregivers' increased sense of resourcefulness and empowerment identified in the present study. However, as Ugalde (2011) and Merluzzi et al. (2011) both point out, self-efficacy measures must incorporate a way to capture more than caregivers' preparedness to undertake the practical tasks of caring for others. These measures must include self-efficacy in terms of the ability of caregivers to care for themselves and their own emotional, psychological needs and interpersonal challenges

The findings in this study indicate that, in addition, to enhanced resourcefulness or sense of 'coping' generally, mindfulness enhances caregivers' ability to 'cope' with the myriad losses and grief characteristic of end-of-life caregiving, as well as bereavement post the death of their significant other. This study shows that mindfulness enables caregivers a different way of approaching grief: a way of being able to acknowledge, allow and engage with their experiences of loss. Paradoxically, this approach enabled them to connect with positive experiences that co-exist alongside moments of pain and difficulty. This study

identifies two key ways in which mindfulness supported caregivers to navigate grief and loss. Firstly, mindfulness enabled caregivers to steady their strong emotions which has been identified in the literature as emotional regulation (Boyle et al. 2017; Farb, Segal & Anderson 2012; Wheeler, Arnkoff & Glass 2017). Secondly, mindfulness provided 'a new grief narrative'. This 'new grief narrative' involves cultivating an ability and willingness for caregivers to acknowledge and engage with their loss: '*you can be in the presence of pain. You can be in the presence of grief*' (F 3), without being immobilised or overwhelmed. This narrative fundamentally challenges long-established messages received by caregivers, that in order to maintain a strong stoic façade, they should avoid or distract from their grief or risk '*falling to pieces*'. It also challenges the stance of caregivers '*fighting against'* the unwanted experiences of loss and grief, for fear that in accepting them, they would invite death closer or convey a sense of giving up.

Across the five domains of benefits from learning and using mindfulness in end-of-life caregiving, identified in this study, a series of positive movements or positional shifts can be clearly identified. Common to all, was the permeating sense of mindfulness enabling caregivers to relate to their experience, self and others in a different, more empowered way, characterised by increased presence, engagement, compassion and connection. As previously noted, findings indicated that these movements into a more mindful space were sometimes brief and that caregivers oscillated between the mindful and more chaotic space characteristic of caregiving, as opposed to a fixed and permanent shift. However, these movements constituted vitally important moments as, in many instances, they were the only moments of calm and ease that caregivers experienced in caregiving.

8.6.2 Reconceptualising Respite in End-of-Life caregiving

On further examination of the third overarching process of the theoretical model developed in this study, 'Gaining in a Landscape of Loss: The Value and Benefit of Mindfulness in End-of-Life Caregiving', another critical finding for discussion is the idea of mindfulness as a new form of respite in end-of-life caregiving. Specifically, this involves reprieve or restoration 'in-place', without the physical removal of the caregiver or care recipient. Respite in this form was constituted of brief, but important moments in which caregivers: (1) repositioned themselves from being entangled and overwhelmed by their thoughts, feelings and experiences of caregiving into a more grounded space, and (2) reconnected with and cared for themselves as a person in their own right. See Figure 13 below.

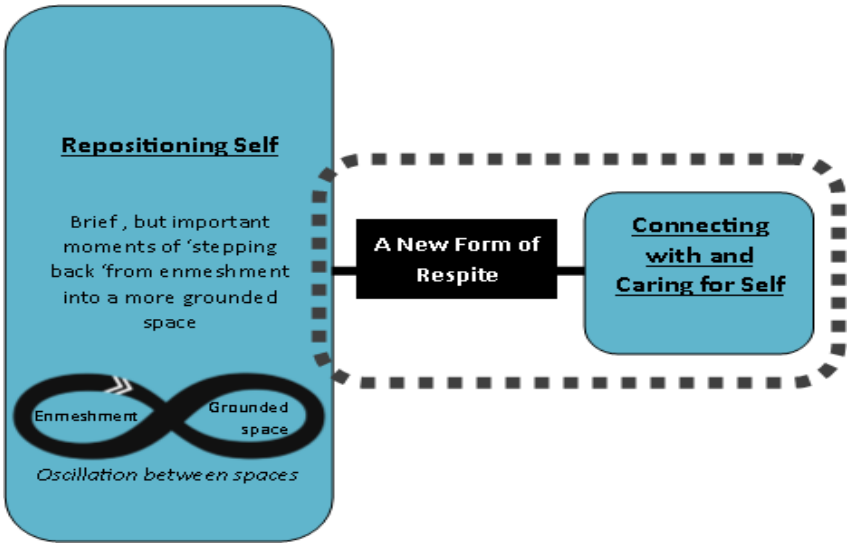


Figure 13: Mindfulness as a New Form of Respite

Respite is variably described in the literature as 'a lull', gaining a 'breathing space', 'a reprieve' or 'break', which well reflects how the participants in this study described the repositioned-space opened up by mindfulness: *'It offers little places to rest in*' (Bill). The respite provided by mindfulness from the physical, cognitive and emotional activities of caregiving, however, significantly challenges traditional perceptions and offerings of respite

in palliative care. Traditional approaches to respite have the separation of the caregiver and care recipient within a disease and burden paradigm to relieve stress and burden. Important moments of respite afforded by mindfulness did not involve the disruption to connection, time and place in caregiving. Instead these moments of reprieve and rest often occurred whilst in the presence of the care recipient amidst undertaking daily activities and roles. Mindfulness could be practised whilst undertaking increasing household tasks, whilst sitting quietly with the care recipient at medical appointments, in the hospital, as their significant other slept or were dying. This resonates with a qualitative, phenomenological study of young caregivers (n=13) in Western Australia which found, through semi-structured interviews, that participants needed to balance their demanding caregiving role with moments of solitude or 'solo activities that were reflective or mindful in nature' (McDougall, O'Connor & Howell 2018, p 577). These findings add weight to emerging research that has suggested respite be reconsidered as a psychological outcome, as opposed to a fixed view of respite as a 'service' only (Strang et al. 1999).

Whilst the value of respite, as restorative time, is widely acknowledged in the literature (McGrath et al. 2006; Strang 2000; Wolkowski, Carr & Clarke et al. 2010) and a commonly reported need by caregivers (Ventura et al. 2014; Zapart et al. 2007), uptake of traditional forms of respite by end-of-life caregivers has been low (Brodaty et al. 2005; Neville et al. 2015). As discussed in Chapter Two, underpinning reasons include feeling responsible to provide care, not wanting to leave their significant other when time is limited (Phillipson, Jones & Magee 2014; Robinson et al. 2009) and perceiving 'time out' as a non-legitimate luxury (Ugalde, Krishnasamy & Schofield 2012). Additionally, the polarisation of carer and care recipient by a burden and deficit-based framing of respite has been identified as a factor impeding caregiver acceptance of respite (Ingleton et al. 2003; Payne 2007,

Wolkowski, Carr and Clarke 2010). In response, authors such as O'Shea et al. (2017b) have advocated the need for a 'relationship centred paradigm of care' to emphasise mutual benefit of respite for both caregiver and care recipient. A new term 'restorative care', as potentially helpful in recalibrating the traditional assumptions of respite, has also been advanced in the literature (O'Shea et al. 2017b). Others have suggested the development of new models of respite, that are more acceptable to caregivers (Harding & Higginson 2003; Wolkowski, Carr and Clarke 2010). Research has seemingly stalled in terms of developing alternative models of respite. Findings from this present study suggest that mindfulness may provide an alternative respite model: a way of enabling caregivers to reposition themselves in relation to what is happening around them, without physically removing themselves or the care recipient and without invoking a subsequent separation and disconnection in the context of limited and precious time.

In addition to describing the experience of mindfulness as opening spaces of calm, ease and rest within their everyday lives, participants in the present study strongly articulated that these spaces of respite were characterised by reclaiming or reconnecting with themselves outside of the caregiver role: '*I could just be me,*' (Laura). These opportunities were described as the only moments they had in the context of caregiving to be themselves and take time for themselves. Caregivers' experience of respite clearly involved a reconnection with a sense of self and a sense of reassurance that whilst life is radically changed and changing there is a sense of 'a me' that is enduring.

The relationship between maintaining a sense of personhood and respite has been identified in the informal palliative care research literature (de la Cuesta-Benjumea 2011; Strang et al. 1999; Upton & Reed 2005). A descriptive model explaining family dementia

caregivers' experience of respite by Strang et al. (1999, p 454), found that the process of 'moving out of' the caregiving role, physically and cognitively, to reclaim a sense of personhood and personal focus, was critical to the experience of respite as restorative, calm and restful. The authors explain:

> Caregivers' description created an image of two spheres of existence. One large and dominating sphere was the caregiving world, whereas a much smaller, but very special sphere was that part of their lives where they experience respite and where they were not caregivers. To be in this special personal space was… where they were free to be themselves, where they could pursue their own interest and activities…they could shed the responsibilities of caring…this notion of movement towards a mental place where they would consider themselves out of the caregiver world (Strang et al. 1999, p 454).

Three processes were identified by Strang et al. (1999) as underpinning caregivers' ability to access respite: (1) recognising their need for a break, often occurring at a point of crisis which threatened their health and the sustainability of care, (2) giving themselves permission to take a break, and (3) information about and encouragement to access respite as a legitimate need. These factors were also identified as important, in this study, as underlying reasons for caregiver willingness and ability to engage in learning mindfulness whilst caregiving. This suggests such factors are important elements in catalysing caregivers to consider and take action around their own needs and self-care.

Strang et al. (1999) model emphasised respite as involving 'getting out of the caregiving world'. The theoretical model developed in the present study, however, found that mindfulness enables a space of respite where caregivers can be themselves and attend

to their own experiences and needs, *within* the caregiving world, not outside of it. While respite is a familiar concept to palliative care providers, the findings in this study unexpectedly offer the conceptualisation of mindfulness as a new approach to respite. This invites a re-conceptualisation of the traditional view and provision of respite as involving the physical separation of the caregiver from those for whom they are caring, which is documented to have been highly resisted in end-of-life caregiving. The experience of respite, as offered by mindfulness, provided not only 'time-out' from the cognitive and physical activities of caregiving, but was also characterised by a reconnection with a sense of self outside of the caregiving role. Additionally, mindfulness supported caregivers to reframe self-care as legitimate and offered manageable moments in which they could care for themselves.

8.6.3 Rethinking Measurement of 'Effect'

There is one final point of discussion regarding the third component, or overarching process of the theoretical model developed in this study, 'Gaining in a Landscape of Loss: The Value and Benefit of Mindfulness'. This point is concerned with how to capture and measure the range of positive effects articulated by the participants in this study, what these have meant in terms of caregiving, and for some, life more broadly:

> *How can you capture what mindfulness gives people? How can you capture what it means to really be there? How do you measure that?* (Ava).

Existing practice of evaluating the effects of learning and using a mindfulness-based approach in end-of-life caregiving have predominantly focused on the reduction of negative symptomology, particularly stress, depression, anxiety and burden. This focus is based on the findings of effect in other populations. However, the findings in the present study did

not yield descriptions of reduced negative mental health effects, but rather elucidated a broad range of enhanced, positive effects such as increased awareness, enhanced connection with self and others, greater sense of self-compassion, empowerment and agency, increased moments of rest, calm and feeling grounded, and an enhanced ability to tolerate discomfort. These findings prompt a reconsideration of the lens through which we view and seek to measure the impacts of learning mindfulness in end-of-life caregiving. They suggest that looking to identify enhanced positive effects, as opposed to the more common burden and disease-based approach that focuses on reduced negative effect, may be more likely to capture the effects of mindfulness-based approaches in this setting. For a number of facilitators in this study, measuring for enhanced positive effects was regarded as important in any context, in order to capture critical aspects of people's experience of mindfulness.

Documented within the existing literature, is a prevailing concern that measures used in MBI research and in caregiver intervention studies more broadly, are often not well matched to potential intervention effects (Oken et al. 2010) and too narrow in their focus on cognitive variables (Berk et al. 2018). Authors such as Ugalde (2011) have asserted that:

> The consequences of using an instrument that doesn't capture the experience of the sample is substantial. For example, an intervention may have a benefit but may lack the appropriate measures to demonstrate an effect (p 195).

This is starkly emphasised in a study by Harding and Higginson (2001), whose quantitative analysis of a short-term self-care intervention yielded no significant effect, however, the qualitative component of inquiry elucidated a range of benefits perceived significant by the caregivers themselves.

The present study lends support to the need for further research to develop and trial measures that more closely match the effects that caregivers report experiencing and which they regard to be beneficial. A place to begin would be to consider ways of measuring the following: decentering or metacognitive awareness, reduced use of avoidance coping, interpersonal connection, self-compassion, and constructs such as empowerment, personal agency or self-efficacy.

In light of the range of complex and interconnected positive effects from learning and using a mindfulness-based approach in end-of-life caregiving elucidated in this study, the findings clearly suggest rethinking how intervention effects are measured in this setting, to ensure that we are *'measuring the stuff that makes the difference'.* Specifically, measuring for enhanced positive effects, rather than reduction in negative symptoms: the outcomes traditionally measured due to the prevailing problem and burden-focused paradigm. Increased attention to constructs such as increased strengths, personal resources, empowerment and appraisal of self-efficacy are indicated.

8.7 Chapter Summary

This study has provided the first known conceptual model to explain the experience of learning and using a mindfulness-based approach in end-of-life caregiving, grounded in the lived experience of caregivers and facilitators who have taught mindfulness in this setting. This discussion chapter has broken down and walked through this model and its key components, comparing these across three bodies of literature or domains of knowledge: informal palliative caregiving, mindfulness-based interventions and specifically the use of MBIs in the setting of informal palliative caregiving.

The next chapter offers a conclusion to this thesis acknowledging the limitations as well as the strengths and contributions of this study. It will examine the implications of study findings for policy, practice and further research and finishes with a personal reflection on the research process and its findings.

CHAPTER 9

CONCLUSION

9.1 Chapter Introduction

This is the final chapter in this thesis. It brings together all the components of the research process outlined in the previous eight chapters. It addresses the strengths and limitations of this study, including whether it has answered its research aims and questions. The implications of study findings for policy, practice and further research are also examined. The chapter concludes with a personal reflection of lessons learnt within the research process, which offers a fitting reply to the personal reflection at the very beginning of this thesis.

9.2 Returning to the Research Problem, Study Aims and Methodology

At the outset of this thesis, a critical review of the literature identified a paucity of evidenced-based caregiver support interventions. Considering the multiple adverse impacts of caregiving, documented over several decades, this provided an unsettling view. More specifically, the review noted a lack of interventions attending to the holistic needs of caregivers, particularly psycho-social, emotional and spiritual needs (Harding 2010, Funk et al. 2010). Interventions that were strengths-focused (Grande et al. 2009; Hughes 2015) and which had been informed and refined by caregiver engagement (Hudson 2005b, Grande et al. 2009, Henwood, Larkin & Milne 2017) were also found to be lacking.

The potential for mindfulness-based interventions (MBIs) to support caregivers and their holistic needs in end-of-life caregiving was investigated through a systematic literature review (Jaffray et al. 2016). MBIs were identified to be effective at decreasing depression

and caregiver burden and increasing quality of life. However, this evidence rested on a small number of predominantly quantitative studies, the greatest number of which focused on dementia caregivers, as opposed to caregivers of people with more rapidly progressing illness, or towards the end of life. Whilst it is noted that qualitative components of inquiry have increased in the last two years, in the form of mixed method study designs, findings are derived from thematic and content analysis, often combining caregiver and patient data, and remain descriptive, rather than interpretive. As such, a lack of an in-depth qualitative understanding and interpretive accounts of the experience of mindfulness whilst caregiving in the last 12-months of life, remain. In-depth examination is lacking, not only regarding the experienced benefits of mindfulness in this setting, but there is also an absence of inquiry into potential adverse effects.

A contention of this present study was that this lack of nuanced understanding was problematic. It was considered problematic because research was continuing to seek quantitative measures of the effects of MBIs in the absence of first understanding what is likely to be affected, from the point-of-view of the people most able to provide insight into this experience, caregivers themselves and those involved in providing mindfulness training in this context. Instead, assumptions were made that measures used to evaluate effects in other client populations would suffice and have application in the context of end-of-life caregiving. This study was critical of such an approach, with the view it would overlook a range of other potentially significant effects and deny the opportunity for caregivers themselves to define what were beneficial and valuable outcomes in the context of caring for a terminally ill family member or friend. Obtaining in-depth understanding of the experience of learning and using mindfulness in end-of-life caregiving was perceived necessary, not only to inform the selection of more sensitive measures to detect effects in

this context, but also to empower caregivers in the co-construction of knowledge and program development. Specifically, such an approach was considered critical to inform the design and delivery of MBIs in the complex, time-sensitive setting of informal palliative caregiving. Additionally, whilst user engagement is recognised as important in developing and refining caregiver interventions (Gysels et al. 2013; Riffin et al. 2015), it has been rarely implemented in either caregiver intervention (Higginson et al. 2013; MacLeod, Skinner & Low 2012) or MBI research (Bazzano et al. 2013).

As a result of identifying these gaps in knowledge and research approach, this study, using a constructivist grounded theory methodology, sought the dual perspectives of mindfulness facilitators (n=12) who had experience in teaching mindfulness to informal palliative caregivers and informal caregivers (n=8) with lived experience of learning and applying mindfulness in the context of end-of-life caregiving. Twenty semi-structured and intensive qualitative interviews were undertaken. Data analysis involved constant comparative methods and increasingly abstracted cycles of coding, employed simultaneously with theoretical sampling and data collection. This process occurred until theoretical saturation was achieved. The analytic outcome was the construction of a substantive grounded theory.

9.3 The Constructed Theoretical Model

This study has developed the first known grounded theory model explaining the process and what it means to learn and use mindfulness as an informal palliative caregiver. This model, entitled, 'The Experience of Learning and Using a Mindfulness-based Approach in End-of-Life Caregiving: A theoretical model', comprises three overarching processes as detailed in the previous chapter. As discussed, the first process derives from caregivers' raw

and confronting narratives of what it is like to care for a family member or friend with a palliative illness: 'Experiencing a World Disrupted: The Context and Characteristics of End-of-Life Caregiving'. This has two key categories: 'The disorientating and loss-filled landscape of caregiving' and 'The self-care disconnect', which offer powerful descriptions of what it is like to care for a family member or friend at the end of life.

'The Process of Learning and Using Mindfulness in a Disrupted World' is the second overarching process, encompassing three key categories: 'engaging with mindfulness', 'supporting factors and overcoming challenges' and 'considering adverse effects'. These categories contain important considerations for further developing and offering mindfulness-based approaches in the setting of end-of-life caregiving to increase caregiver engagement, enhance the experience of benefit and mitigate the limited, but potential, adverse effects.

The third overarching process in the theoretical model developed in this study: 'Gaining in a Landscape of Loss: The Value and Benefit of Mindfulness in End-of-Life Caregiving', outlines the positive experiences of learning mindfulness as an informal palliative caregiver and what these mean to caregivers. Five conceptual categories depicting benefit are identified, including: 'repositioning self'; 'engagement with the full range of experience'; 'connecting with and caring for self'; 'strengthening relationships' and 'realising a resourceful and empowered self'. This last category 'realising a resourceful and empowered self' also expressed the quintessential value of learning and using mindfulness in end-of-life caregiving. Inherent in all categories of benefit was a powerful sense of positive movement, explored in the discussion as 'positional shifts'.

Additionally, mindfulness is identified and explained as a new form of respite: a chance for caregivers to gain brief, but important moments of stepping out of enmeshment and overwhelm into a more grounded space. This space enables caregivers to experience a sense of personhood outside of their caregiver role but in a way that does not mandate separation from the care recipient. A critical finding of mindfulness providing a way for caregivers to legitimise and action caring for themselves and their own needs is also identified as a significant finding in this study.

9.4 Study Limitations

The myriad of decisions made in any study implicitly carries opportunities to either strengthen or limit research quality and rigour. The following section offers a critique of the limitations in the present study, their implications for interpreting study findings and for future research. This is followed by a critique of study strengths and contribution to research, policy and practice.

9.4.1 Sample

A number of limitations to this study are acknowledged. Firstly, the sample consisted overall, of white, educated, middle-class participants, which is a limitation shared with existing mindfulness and palliative care research more broadly. Additionally, the small number of participants could be regarded as a study limitation. However, the sample of 20 participants interviewed in this study is consistent with a constructivist grounded theory methodology, which advocates that theoretical saturation is likely achieved between 20 and 30 interviews with sufficiently detailed and nuanced data (Creswell 2013). Whilst the model developed in this study explains the experience of learning and using a mindfulness-based

approach in end-of-life caregiving in a way that represents the lived experience of the participants in this study, these findings cannot be considered representative of, or generalisable, across all informal palliative caregivers. Research undertaken with a different population of caregivers may yield different findings. It would be interesting to compare the findings of a similar grounded theory study in different national or international settings, potentially targeting more metropolitan-based caregiver samples and those who are in receipt of palliative or supportive services. This study, however, consistent with a qualitative approach and use of constructivist grounded theory methodology, did not seek broad generalisations, but rather to value the deep contextualisation of findings in time, space and culture.

9.4.2 Features of the Interview Process

The method of interviewing the majority of mindfulness facilitators by phone or skype in Phase One of this study, could also be perceived as a limitation. Within the literature, face-to-face interviews are considered the best approach to develop rapport and facilitate participant sharing of experience, especially in the context of emotional or sensitive topics (Deakin & Wakefield 2014). However, considering the geographical distance between the researcher and the mindfulness facilitators, seven of whom lived interstate and three internationally, face-to-face interviews were not feasible within the scope of the study, nor within its financial resources. Feedback from the mindfulness facilitators indicated that the remote method of interview was experienced as acceptable. Some expressed that the interview flowed naturally or felt easy, with one facilitator stating, 'It's been good, I've had the chance to say everything I need to' (F 9). Additionally, many facilitators chose to share their own very personal end-of-life caregiving and bereavement

experiences, thus evidencing the achievement of rapport, connection and sense of safety with the researcher, despite the physical separation.

Another possible limitation of this study was not undertaking repeat interviews with participants to increase the rigour of theoretical sampling and more robust testing of the emerging grounded theory. However, in light of the vast geographical distances between the researcher and the mindfulness facilitator participants, and not wanting to invoke an increased sense of burden on caregivers caring at the end of life, or in bereavement, a considered decision was made to forgo repeat interviews in this study. Instead, data collection continued, and existing data was re-analysed, as the emerging theory developed, until theoretical saturation was achieved. Clarification and explanation were sought during the interviews as needed.

9.4.3 Potential for Bias

In terms of the potential of bias as a limitation in this study, three issues are acknowledged. Firstly, as addressed in the discussion, it is acknowledged that mindfulness facilitators may have personal bias about the value of mindfulness-based interventions. They are, however, experts in the delivery of this program of work and their views were considered important. Secondly, it is possible that only caregivers who had positive experiences of learning and using a mindfulness-based approach in end-of-life caregiving elected to participate in this study, thus providing a skewed view of benefit and the finding of no risk. Thirdly, all qualitative studies encounter scepticism of the effect of researcher bias on the research process and findings. Consistent with a constructivist grounded theory methodology, it was not the intention for the researcher to take the position of an objective, distanced 'collector' of data. Rather the researcher positioned herself from the

beginning of this study as someone, who in dialogue with research participants, would reflexively co-construct an interpretive understanding of the experience of learning and using a mindfulness-based approach in end-of-life caregiving. It was explicitly acknowledged that researchers do not come as a 'blank-slate' to the research process. Therefore, the researcher chose to be 'upfront' in terms of her own experiences as a former palliative care social worker, as a daughter having cared for her father, dying of bladder cancer, and as someone who has learnt and uses mindfulness in her life. Throughout this study, the adoption of rigorous and reflective journal and memo-writing, and frequent supervision sessions, however, have served to ethically monitor, critique and guard against personal assumptions and values unconsciously shaping the research outcome.

9.4.4 The Place of the Literature Review in Grounded Theory

Undertaking a systematic literature review at the beginning of the research process, could be regarded by some as a limitation in this constructivist grounded theory study. This would be underscored by the view that prior knowledge of the research literature could contaminate and undermine the development of theory grounded in the study data. However, a counter view is that one always has some degree of prior knowledge and assumptions about one's research topics and that the need to be critical and reflexive to ensure these do not unconsciously bias the research process remains the central issue. Further, the dissertation process requires researchers to establish a case for their proposed study, in the context of existing literature. In light of this, the literature review undertaken as part of this study, focused on establishing what research had been undertaken in the field of MBIs for informal palliative caregivers and whether there was evidence of effectiveness. The rationale being, that this would identify the gaps in the existing literature and inform

the thinking about and design of the present research study. It was the identification of no in-depth qualitative research studies or conceptual models to explain the experience of learning and using a mindfulness-based approach that underpinned the decision to conduct a qualitative, constructivist grounded theory study. Due to the lack of existing in-depth nuanced knowledge, the possible influence of the systematic literature review on this grounded theory study, whilst not entirely discounted, is regarded to be low. On deciding to use a grounded theory methodology for this study, the two in-depth reviews of the informal palliative caregiving and mindfulness- based intervention literatures, were delayed until after data analysis.

One final point regarding potential limitations of this study must be noted. Whilst identifying several issues requiring consideration in the design and offering of mindfulness-based approaches in end-of-life caregiving, this study was not fully able to answer the question about what MBIs need to look like in this setting. The small sample size and methodology does not lend itself to establishing a broad consensus on the multiple and nuanced elements requiring consideration in the design and implementation of MBIs for informal palliative caregivers. This study provides some preliminary insights that could guide further research, perhaps in the form of larger multi-site studies and subsequent survey-based designs, to further test the key elements for effective, accessible mindfulness-based programs in this setting.

9.5 Study Strengths, Contributions and Implications

This study offers a number of methodological strengths and contributions to research and practice. This section contains two key parts. Firstly, it briefly articulates the methodological strengths of this study, the contributions to existing research and

implications for future research. The second section discusses the strengths and contribution of study findings, specifically in terms of its generation of new knowledge regarding the experience and effects of mindfulness in end-of-life caregiving and the implication for practice. Within each section, the four key measures of quality and rigour advanced in constructivist grounded theory methodology will be addressed in regard to the study and examples provided. These evaluative measures include credibility, originality, resonance and usefulness.

9.5.1 Methodological Strengths

This study has several methodological strengths which contribute in important ways to the existing literatures, both in the field of MBI research for informal palliative caregivers and in terms of informal palliative caregiver research more broadly. These are outlined and substantiated below.

An Explicit Focus on Caregivers and Their Own Health and Wellbeing

The first strength of this study is its adoption of an explicit research focus on exploring how learning and using a mindfulness-based approach in end-of-life caregiving impacts caregivers' experience, health and wellbeing, irrespective of gains in care quality or sustainability. This contrasts strongly with much of the informal caregiver intervention literature. For example, many of the targeted outcomes of caregiver interventions are orientated towards enhancing and sustaining care of the significant other, as opposed to enhancing caregiver health, wellbeing and self-care as a legitimate aim in and of itself (Dionne-Odom et al. 2017a; Johnston 2012).

The purposeful approach in this present study, to recast the focus onto caregivers and their own experience from having learnt a mindfulness-based approach in end-of-life caregiving, was explicitly conveyed throughout the interview process. Caregivers responded candidly and spoke in considerable detail about themselves and their own journey and many (Jason, Gwen, Ava, Laura, Bill and Lorna) shared difficult experiences they had seldom spoken about before.

The Value of a Qualitative Approach and Use of Constructivist Grounded Theory

Whilst qualitative research is commonly utilised in informal palliative caregiver research to describe the caregiver experience, needs and impact, a qualitative approach is significantly less utilised in caregiver intervention research (Craig et al. 2008; Harding et al. 2002; Hudson, Remedios & Thomas 2010; Lou et al. 2017) and minimally so in MBI research in the informal palliative caregiving setting (Dharmawardene et al. 2016; Jaffray et al. 2016). As identified in the literature review in Chapter Three, only eight of twenty-one mindfulness-based intervention studies for informal palliative caregivers incorporated a qualitative component of inquiry, all as part of mixed method study designs. This present study has demonstrated the value of in-depth qualitative research and its focus on allowing caregivers to richly describe their experience of learning and using mindfulness in the context of end-of-life caregiving and to define what they consider are beneficial outcomes and why. This study, by using a constructivist grounded theory approach, has also demonstrated the value of moving beyond pure description, to offer theoretical understanding of what it is like to learn and use mindfulness in the end of life caregiving, which also accounts for the frequently neglected, social and cultural contexts.

Sampling and Recruitment: Seeking and Amplifying the Voices of Hidden Caregivers

Another significant methodological strength of this study relates to its sampling and recruitment methods. This study valued 'user engagement' and purposefully sought the lived experience of caregivers to understand the effect and key elements of MBIs in end-of-life caregiving. Caregiver engagement in designing and implementing caregiver interventions has long been recommended in the literature (Riffin et al. 2015; Gysels et al. 2013) but seldom undertaken (Higginson et al. 2013; Hudson et al. 2012; MacLeod, Skinner & Low 2012). This study was also able to recruit and amplify the voices of hidden caregivers: those frequently neglected in informal palliative caregiver intervention research. These include rural caregivers, those not connected to palliative care or supportive services and those who are actively caregiving at the end of life.

For example, in a departure from many of the published caregiver intervention studies, seven of the eight caregivers in this present study had the experience of caregiving in a rural area. This study also recruited caregivers, who were caring in the absence of palliative care or supportive services (Gwen, Ava, Laura, Molly), or who had only accessed these services very late in the towards the end of their family members' life (Bill, Jason, Sarah, Lorna). This is important as the prevailing research rests on recruiting caregivers from within palliative and hospice care organisations, which may not reflect the experience of individuals caring outside of these supports (Steinhauser et al. 2006). Findings in this present study of the raw and often dark portrayals of the caregiving experience, despite the researcher's intent to listen for and follow leads of positive caregiving experiences, may support this hypothesis.

This study also demonstrated that it is possible to engage informal palliative caregivers in research whilst actively caregiving, despite the intensity and challenges of this

experience. Four of the eight caregivers were still actively caregiving at the time of study participation. This study contributes to an increasing literature base that is challenging the assumption that caregivers are too vulnerable to participate in research at this time (Aoun et al. 2017; Gysels, Evans & Higginson 2012; Steinhauser et al. 2006). By not extending equal opportunities to all caregivers to participate in research, many caregivers have been denied the opportunity to inform understanding about caregiving and the required supports (Grande et al. 2009; Hepgul et al. 2018; Steinhausser et al. 2006). Whilst most caregivers in the present study understandably became emotional and cried at different points in the interview as they recounted aspects of their caregiving journey, all caregiver participants spoke about having experienced the interview process as empowering. Specifically, they expressed feeling positive about having contributed towards enhancing support options for other caregivers.

Triangulating the perspective of caregivers with mindfulness facilitators who had experience with teaching mindfulness in the informal palliative caregiving setting, enhanced rigour and trustworthiness of the data and added depth to analysis. Mindfulness facilitators could contrast their observations of how informal palliative caregivers have engaged with and experienced mindfulness with other client populations. The decision to recruit mindfulness facilitators locally, nationally and internationally was based on capturing as many facilitators as possible with experience of mindfulness in this setting, which was judged, based on the literature, to be rather scarce. Furthermore, it allowed the identification of processes that transcended different cultures, such as 'The self-care disconnect', which was prominent in the data from facilitator interview participants in Australia, USA, Malaysia and the UK.

Empowerment and the Research Process

Another proposed strength in the present study was the adoption of a flexible, empowering approach in terms of data generation. Significant consideration and effort occurred in relation to sharing information about the research process and minimising power asymmetry between research participants and the researcher. This included adopting a warm, humanistic approach in the interview process, positioning myself as having once been a palliative care social worker and a carer for my dying father. This contextualisation or explanation of how these experiences informed my interest in the research topic were considered important.

Further, efforts to support the empowerment of research participants included offering them choice in terms of when, where and by what means they would like to participate in a research interview. This was considered particularly important for caregivers who were juggling multiple demands and responsibilities and likely felt a degree of vulnerability in talking about their experience of end-of-life caregiving and how mindfulness influenced this. Care was taken to ensure that participants felt safe, respected and able to express their experience in their own terms, without concern of them offering 'right' or 'wrong' answers or being judged for what they said.

Credibility of Analysis

One final methodological strength claimed in this study relates to the in-depth and rigorous process of data analysis. Credibility is a key criterion of quality and rigour in constructivist grounded theory methodology. This involves an 'intimate familiarity' (Charmaz 2006, p 182) with the data and topic, systematic comparisons between categories and defensible connections between the data, its analysis and key arguments. This study

demonstrates credibility in its rigorous process of detailed familiarisation with the interview transcripts, initial line-by-line 'in vivo' coding' and the progression to focused and theoretical coding which enabled higher abstraction of the key data categories. Evolving categories were constantly compared with existing and subsequently collected data until theoretical saturation was reached at 20 interviews. Memo-writing and reflexive diary entries augmented the process of analysis and theory development. These processes also monitored personal assumptions and ensured analysis remained grounded in the data. Each stage of data collection and analysis has been provided in detail in this thesis, offering transparency of the research process. Additionally, substantial participant data in the form of substantiating quotes was provided in the presentation of results to enable the reader to judge for themselves, the credibility and defensibility of study findings.

9.5.2 Implications for Future Research

Research into the application and effects of MBIs for informal palliative caregivers is a relatively new field of inquiry. Whilst this study has contributed a more nuanced and theoretical understanding of what it is like to learn and use a mindfulness-based approach in end-of-life caregiving, further research is required. This study and its findings engender three main implications for future research. These include the following: (1) research design and methodology, (2) sampling and recruitment, and (3) the identification of three focus areas requiring greater support.

Research Design and Methodology

Firstly, greater use of rigorous, in-depth qualitative designs in caregiver intervention research are strongly encouraged to generate more nuanced understanding and to help guide more robust quantitative studies in terms of what is likely to be affected. Qualitative

approaches, as demonstrated in the present study, are well suited to the exploration of complex interventions, where the mechanisms of action are unclear. Methodologies that seek to elucidate social and cultural factors, such as the dominant norms and narratives that shape caregivers' experience of end-of-life caregiving, their engagement with support interventions (MBI or any other, and how they experience them, are also further encouraged.

Sampling and Recruitment: User Engagement and Recruitment of Hidden Caregivers

A second implication for further research, resulting from this study, is that a renewed commitment to user-engagement in informal palliative caregiver intervention research is strongly encouraged. Whilst seeking caregiver participation and voice in the process of intervention development and evaluation is commonly espoused, it is frequently neglected in caregiver intervention-based research (Grande et al. 2009; Hudson, Remedios & Thomas 2010, Candy et al. 2011). Authors, such as Harding and Higginson (2001), strongly advocate the need to ensure interventions are acceptable and feasible to caregivers, a sentiment echoed by (Craig et al. 2008; Hepgul et al. 2018; Higginson et al. 2013). Regardless of study design, it is suggested that user-engagement, or recruiting caregivers with lived experience of having learnt and used mindfulness in this setting is critical to inform the development, and evaluation of MBIs in this emerging field of enquiry.

Further studies are also encouraged to seek the involvement of caregivers frequently overlooked, not only in the MBI literature for informal palliative caregivers, but also in caregiver research more broadly. These include: people who are caring in the context of more rapidly progressing diseases as opposed to a predominant focus on dementia, those caring in the absence of palliative or other supportive services, rural caregivers and those

from diverse ethnic backgrounds. The voice and experience of lesbian, gay, bisexual, transgender and intersex (LGBTI) caregivers are noted as being particularly absent in the caregiving literature, requiring redress (Bristowe et al. 2018; Cloyes, Hull & Davis 2018). This will work towards achieving a more representative understanding of the experience of end-of-life caregiving interventions. There is also a need for a greater number of prospective research designs in order to understand how caregivers are experiencing the intervention at the time, rather than through a retrospective lens, as well as longitudinal research that follows caregivers and changes over time.

Focus Areas for Future Research

Three focus areas for future research are additionally suggested. Firstly, more focused, in-depth research is required to generate understanding about the factors that give rise to and maintain caregivers' reluctance to care for themselves and their own needs, as well as those that enable a shift in this reluctance. This is important as until broader work is undertaken to address resistance towards self-care, engaging more caregivers in MBIs or any other support interventions will remain difficult. The conceptual rendering of this reluctance as 'The self-care disconnect' in this present study, may spur more concerted efforts to investigate interventions that specifically target and seek to ameliorate this pervasive phenomenon, which to date has received little research attention, despite calls to do so (Aoun et al. 2005a; Harding & Higginson 2001).

Secondly, the present study acknowledges having only been able to provide preliminary considerations, in terms of thinking about what MBIs may need to look like in this setting. This leaves a significant opportunity for larger, more focused research to take up the challenge of generating nuanced understanding in this area to further guide policy

and practice. Future research should explore and evaluate a broader range of MBIs in the setting of informal palliative caregiving, as the findings from this present study strongly suggest that a one-size-fits all or blanket-approach may be indicated in this setting. Specifically, exploration of adapted mindfulness-based approaches could include: (1) lower-dose interventions, with fewer and shorter sessions and practice requirements, (2) individual as well as group-based programs, (3) remotely delivered programs including the use of online, telephone, and smart phone apps. These approaches could be considered, in addition to the traditional intensive, face-to-face method. It would also be valuable to determine whether the desire for more person-centred, flexible options for learning mindfulness in end-of-life caregiving, identified in this study, is shared across end-of-life caregivers broadly or a function of rurality.

Thirdly, future research should reconsider the predominant focus on measuring primarily for the reduction of negative symptomology, when evaluating the effects of learning and using a mindfulness-based approach in end-of-life caregiving. The findings in the present study indicate that measuring for enhanced positive effects may be more likely to capture the effects of mindfulness-based approaches in this setting. Future research is required to develop and trial measures that more closely match the effects that caregivers report experiencing. Increased sense of 'coping', whilst a term that jars uncomfortably against the social work paradigm for its negative and judgement-based connotations, was the most commonly used word by the caregivers in this study. It would be valuable for further research to explore the constructions of coping, what it looks like, what it means to caregivers, the implications for how they experience themselves, end-of-life caregiving and their willingness to access support interventions. In addition, measures are required to detect meaningful movement or change in how caregivers relate to their experience, self

and others because of learning mindfulness. Whilst most of the MBI research uses pre and post measures, authors such as (Goldin & Gross 2010; Harding et al. 2011; Oken et al. 2010) have suggested that measuring effects during interventions may give a better sense of individuals' experience of benefit and what this means at the time.

9.5.3 New Knowledge and Implications for Practice

The final strength or contribution of this study to be discussed is its generation of new knowledge regarding the experience of learning and using a mindfulness-based approach in end-of-life caregiving. Five significant, specific findings and their implications for practice will be highlighted: (1) a new theoretical model, (2) mindfulness as an approach to self-care, (3) a new approach to respite, (4) considerations of how to offer MBI in end-of-life caregiving, and (5) a greater focus on care for caregivers. Connection between study findings and the constructivist grounded theory criteria for rigour and quality will also be drawn.

A New Theoretical Model

Previous studies have not explored in depth, nor advanced more than a descriptive account of what it is like to learn and use a mindfulness-based approach whilst caring for a family member or friend at the end of life (Jaffray et al. 2016). This qualitative study offers the first conceptual model to explain, in-depth, the experience of learning and using a mindfulness-based approach in end-of-life caregiving, grounded in the lived experience of caregivers and those who have taught mindfulness to informal palliative caregivers. This demonstrates a key criterion of quality and rigour advanced in constructivist grounded theory, that of 'originality' (Charmaz 2006).

The holistic, complex and detailed conceptualisation of this process also demonstrates the evaluative criteria of 'resonance', a third criteria of rigour and quality in constructivist grounded theory (Charmaz 2006). In addition to 'credibility' and 'originality' previously discussed, resonance can be described as the degree to which a study sensibly conveys 'the fullness' of a studied experience in relation to context and its meaning to those who have lived it. This qualitative study was specifically designed to seek and elucidate how caregivers experienced and made sense of learning and using mindfulness, whilst caring for a family member or friend at the end of life and what was meaningful for them in this experience. This study demonstrates 'resonance' by identifying, not only the range of benefits that caregivers' experienced, but also the quintessential meaning of these diverse positive effects. This 'meaning' was the realisation of a resourceful, empowered self, or sense that it was possible for them to navigate and deal with the challenges of caregiving, in the context of ordinarily feeling very disempowered.

Many findings of benefit from learning and using mindfulness in end-of-life caregiving have been discussed throughout this thesis. Further, the significance, value and meaning of these benefits across a range of interpersonal and intrapersonal domains have been distilled. However, in terms of implications for practice, two key findings are emphasised. This study has found that MBIs offer the opportunity for palliative services to address two significant gaps in regard to caregiver interventions: a lack of self-care approaches and the need for new models of respite.

Mindfulness as a Self-care Approach

As discussed in the literature review of Chapter Two, existing caregiver interventions have predominantly focused on the provision of information and psychoeducation designed

to increase caregiver preparedness and self-efficacy in caring for their significant other, as opposed to being resourced to care for themselves. Most of these interventions have located the expertise in the health professional, as opposed empowering caregivers to be an active participant in efforts to support their own resilience to manage difficult experiences. Additionally, interventions with a holistic focus, that attend to the multiple domains of caregiver health and wellbeing, for example, physical, emotional, psychological, social and spiritual, are also lacking (Applebaum et al. 2014; Duggleby et al. 2007; Harding et al. 2012b). The findings in this present study strongly suggest that MBIs may address these identified gaps by offering an empowering, holistic self-care approach that validates the importance of and provides a 'manageable' means for caregivers to engage in self-care. Additionally, MBIs were found to offer caregivers a resource that was self-sustaining and applicable to other aspects of their lives, beyond initial instruction. In light of these findings, services may consider trialling MBIs to offer caregivers another resource, beyond information and practical help, to support them to meet the demands of caregiving.

Mindfulness as a New Form of Respite

MBIs may provide services with a new model of respite that doesn't involve the separation of the caregiver and the care recipient. This is important as it is well documented that caregivers frequently report an unmet need in terms of securing moments of rest or respite from caregiving because of not wanting to leave the person for whom they are caring. In contrast, mindfulness-based approaches support an experience of respite 'in place' which may be more acceptable to a caregiver in the context of limited time. MBIs can also be regarded as 'strengths-based' approaches in that they focus on increasing internal resourcefulness and innate capacity for balance and wellbeing, as opposed to the deficit-

based view more traditionally associated with respite. This key finding of mindfulness as a new form of respite, provides another demonstration of the constructivist grounded theory criteria of 'originality'. It offers a novel way forward to reconceptualise respite in the informal palliative caregiving setting.

How to Offer Mindfulness-Based Approaches in End-of-Life Caregiving

Study findings recommend that increasing the number of caregivers who are offered the opportunity to learn mindfulness requires health providers to receive more information about, and experiential exposure to, mindfulness-based approaches and their benefit. A systems approach is advocated in response.

Findings also strongly indicate that in the context of end-of-life caregiving, there is a need to rethink 'a-one-size-fits-all' model or blanket-approach to offering mindfulness that is more commonly applied in other populations. In consideration of the time constraints and challenging features of the caregiving landscape, a more flexible, person-centred approach is indicated. The finding that all caregivers received benefit regardless of type of mindfulness-based approach, duration of sessions and variable amount of home practice, suggests that rather than being prescriptive regarding format, dosage or timing, a range of options for learning mindfulness is possible.

Challenging the common practice in the informal palliative care setting of existing staff facilitating caregiver support programs, study findings indicate the importance of mindfulness programs being delivered and supported by skilled and experienced mindfulness facilitators.

Offering adapted mindfulness-based approaches has implications for securing funding to run mindfulness programs in the informal palliative care setting. Funding bodies

are more familiar, and arguably more comfortable, with the group-based manualised approaches for teaching mindfulness. This is because such approaches are the most evaluated in the literature, have a manualised structure for consistency, can be delivered to many people at once and are therefore cost effective. Arguing for alternative mindfulness models will be a challenge, but one worthy of pursuing. Similarly, arguing for funds to secure skilled and experienced mindfulness facilitators will also require additional thought and justification, as will rethinking and considering a broader range of measures. For example, study findings suggest that measuring for reduction in negative symptoms and adverse effects of caregiving, which in all likelihood may not change due to escalating care demands as death comes closer, is not the way to proceed in end-of-life caregiving. Instead, measures that focus on detecting enhanced positive effects such as increased sense of personal agency, connection with and compassion towards self and others and the ability to encounter difficulty would be more appropriate.

Finally, whilst there have been no reported adverse effects of informal palliative caregivers learning mindfulness, no studies have specifically inquired into the experience of, or the potential for, adverse effects. Study findings that no caregivers in this study experienced adverse effects from learning mindfulness, nor anticipated adverse effects for other caregivers, suggest that we may not need to be overly concerned with potential risk of offering mindfulness-based approaches in end-of-life caregiving. With significant prompting, the facilitators in this study identified a small number of potential adverse effects for caregivers with pre-existing mental health issues. However, the presence of skilled, experienced and supportive mindfulness facilitation could mitigate these. The findings in this study, are important in terms of responding to potential caution and concern in the practice environment regarding the possibility of mindfulness-based approaches causing

additional burden or difficulty for caregivers, who are already conceptualised as a vulnerable population.

A Greater Focus on Care for Caregivers

Finally, study findings indicate that caregivers are still encountering challenges connecting with palliative and supportive services until late in their significant other's disease trajectory. Additionally, when caregivers connect with services they often express feeling invisible and not recognised as individuals with their own needs, separate from those of the care recipient. This, coupled with their own strongly-held view that taking care of themselves and their needs is not a legitimate pursuit, means that for the caregivers in this study, caregiving was largely an unsupported and lonely experience. This finding implores enhanced attempts to promote the benefit of early referral and connection to palliative and supportive services, especially in rural areas.

Study findings of a profound self-care disconnect among informal palliative caregivers also has significant implications for practice. In the absence of a concerted effort to redress 'The self-care disconnect', the number of caregivers accessing mindfulness-based interventions, or any other support intervention, will remain limited. Findings in this study specifically point to the need to alter the prevailing narrative of self-care as selfish, born from the transactional, binary perception that caring for self comes with the cost of caring less for their significant others. Health providers are regarded as pivotal in challenging the dominant messages of self-care as selfish. They are well-placed to promote increased awareness and legitimacy of caregivers taking care of themselves and their own needs in

caregiving, both in terms of enhancing their own health and wellbeing, and in sustaining quality care of their significant other.

Usefulness

One final comment regarding the strengths and contributions of this study, relates to the last criterion for rigour and quality as advocated by constructivist grounded theory. This criterion denotes the 'usefulness' (Charmaz 2006) or application of study findings to everyday real-world situations and/or to future research. As previously discussed, a key strength of the developed conceptual understanding of mindfulness in end-of-life caregiving, is its potential to inform practice, specifically, what, how and why you might offer mindfulness training to end-of-life caregivers. Study findings also challenge the traditional offering of respite in end-of-life caregiving, with mindfulness proposed as a new and potentially helpful form of respite that doesn't involve the physical separation of the caregiver and the care recipient. Findings also prompt a rethink in terms of how future studies might seek to measure the effects of mindfulness-based approaches in end-of-life caregiving and spur greater research attention to address 'the self-care disconnect'. These are all examples of the usefulness of the study findings to real-life practice, dynamics and situations. Funk et al. (2010, p 602) poignantly emphasised that offering useful information for the purpose of policy and practice, whilst honouring the nuance of participant experience, is not an easy task:

> The challenge for future qualitative research in family caregiving at end of life is to generate information that is useful for policy makers and practitioners while

remaining true to the richness and complexity of individual, contextualised experience.

This endeavour has been at the heart of this study.

9.6 Chapter Summary

This chapter, before offering a critical reflection on the limitations and strengths of the study and implications of the study findings, drew together all the elements of the research process to provide an aerial view of the landscape covered in this thesis. This thesis will conclude by offering a final personal reflection.

A PERSONAL REFLECTION

Whilst the topic of enhancing informal caregivers' support is a pertinent, social, cultural and political issue, it is also a very universal and personal issue: one that will impact you and I, and all those we care about, perhaps many times throughout life. As such, I choose to end this thesis with a final personal reflection of a number of key learnings. This functions as an appropriate bookend to the start of this thesis where I introduced myself, my experience and what brought me to this research.

Learning One

In regard to my first key learning, this study began with a view that mindfulness may be of some benefit to informal palliative caregivers as they face the multiple, loss-filled challenges in caring for a significant other at the end of life. However, this was balanced with significant scepticism as to whether it would be possible for caregivers to learn and use mindfulness in such a setting. This setting, from my personal and professional experience, was marked by uncertainty, a deficit of time and a deeply felt commitment to care. I was very surprised to learn that for most of the caregivers interviewed, it was the very presence and impact of these challenges that prompted them to learn mindfulness. I reflected on my own experience of caring for my father, of feeling overwhelmed and adrift from any resource to help steady or support me to manage the difficult moments of his protracted diminishment and dying. Would I have chosen to learn mindfulness at that time even if it were offered? Even if I knew, the benefits of mindfulness, as spoken bravely by the

participants in this study? I am still not sure. However, if I could have engaged with mindfulness, if someone had sat with me in the courtyard as I rocked by baby to sleep and supported me to not distract from my intense feelings, to connect with my inner resourcefulness and be more fully present with Dad, even in the difficult hours, I wonder how different my experience may have been.

Learning Two

The second key learning for me, over the course of this research, is how I have reconsidered the importance of brief, but important moments or spaces to rest, restore and tune into our inner lives, as opposed to fashioning large and elaborate to do so. The caregivers in this study have taught me that mindfulness can happen in little moments here and there, even amidst one of life's most intense and challenging experiences, end-of-life caregiving and that these little moments can 'make a big difference'. These sentiments have also resonated with hospice care volunteers and other health professionals with whom I have shared these findings. Interestingly enough, others within my sphere such as parents in my peer group, childcare workers and teachers have also related to these findings.

Learning Three

Thirdly this research has also revealed to me how wedded we can be to ideas about finding 'the best way' to do something. I was hopeful that this research would quickly and definitively tell me what MBIs need to look like in this setting, to enable the undertaking of a series of robust pilot studies. Instead, I have been humbled and reminded that individual needs and circumstances are variable. The way forward in this field, I have learnt, is to be mindful, open and curious about what might work best for whom, in what context and to

provide a range of options, respecting and enabling caregiver self-determination in terms of what time and in what format to learn mindfulness.

To finish, the quote by Lao tzu, which I had stick-taped to the wall in my office at the beginning of this PhD journey, seems an appropriate reference with which to conclude this thesis. It reads:

> Do you have the patience to wait
> Till your mud settles and the water is clear?
> Can you remain unmoving
> Till the right action arises by itself?

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APPENDICES

Appendix 1: Literature Review Search Strategy

MEDLINE SEARCH STRATEGY THROUGH PUBMED

1	palliative care [mesh]
2	palliative care [tw]
3	palliat* [tw]
4	palliative [tw]
5	palliative treatment [tw]
6	palliative medicine [tw]
7	palliative therapy [tw]
8	Terminal Care [mesh]
9	terminal care [tw] OR terminal* [tw]
10	terminally ill [mesh]
11	terminally ill [tw]
12	hospice care [mesh]
13	hospices [mesh]
14	hospice care [tw] OR hospice* [tw]
15	"end of life care" [tw]
16	"end of life" [tw]
17	death [tw] or dying [tw]
18	((advanced or end-stage or terminal* [tw])) AND (disease* or illness* or cancer* or malignan* [tw])
19	advanced cancer
20	advanced and cancer [tw] Or advanced and carcinoma* [tw] or advanced and neoplasm* [tw] or terminal* and cancer [tw] or terminal* and carcinoma* [tw] or metastatic and cancer [tw] or metastas* and cancer* [tw] or metastat* and carcionma* [tw] or metastas and carcinoma* [tw] or metastatic and neoplasm* [tw] or metastas* and neoplasm* [tw]
21	liver failure [mesh]
22	liver failure [tw]
23	heart failure [mesh]
24	heart failure [tw]
25	cardiac failure [tw]

26 Kidney failure [mesh]

27 kidney failure [tw]

28 renal failure [tw]

29 amyotrophic lateral sclerosis [mesh]

30 ALS [tw]

31 Motor Neuron Disease [mesh]

32 Motor Neuron disease [tw]

33 acquired immunodeficiency syndrome [mesh]

34 AIDS [tw]

35 Dementia [mesh]

36 dementia [tw]

37 alzheimer Disease [mesh]

38 alzheimer* disease* [tw]

39 parkinson disease [mesh]

40 parkinson disease [tw]

41 neurodegenerative diseases [mesh]

42 neurodegenerative disease* [tw]

43 cardiovascular diseases [mesh]

44 cardiovascular disease* [tw]

45 Stroke [mesh]

46 stroke [tw]

47 cerebrovascular accident* [tw]

48 Multiple SClerosis [mesh]

49 multiple sclerosis [tw]

50 #1 - #49 by OR

51 caregivers [mesh]

52 caregiv* [tw] or carer* [tw] or care giv* [tw]

53 family or families or parent* or friend* or relative* or spouse* or partner* or husband* or wife or wives or child or children or close person* or significant other* [tw] AND (care* or caregive* or care giv*) [tw].

54 #51 or #52 or #53

55 Mindfulness [mesh] or Mindfulness [tw]

56 #50 AND #54 AND #55

Appendix 2: Thesis Publication: A Systematic Literature Review

PALLIATIVE MEDICINE

Review Article

Palliative Medicine
1–15

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Evaluating the effects of mindfulness-based interventions for informal palliative caregivers: A systematic literature review

Linda Jaffray[1], Heather Bridgman[2], Miranda Stephens[1] and Timothy Skinner[3]

Abstract

Background: There is a need to identify proactive, evidence-based interventions to support informal palliative caregivers. Mindfulness-based interventions, evidenced in the literature as providing physical and mental health benefits for diverse populations, may have application in the setting of palliative caregiving.

Aim: To describe, evaluate and synthesise the peer-reviewed literature on the effects of mindfulness-based interventions for informal palliative caregivers.

Design: A Systematic Literature Review according to the Preferred Reporting Items for Systematic Review and Meta Analyses guidelines and a Narrative synthesis.

Data sources: The Cochrane Library, CINAHL, MEDLINE, PsycINFO and EMBASE databases, searched from inception to February 2014 and references of included studies.

Results: A total of 13 articles, reporting 10 studies ($n=432$ participants) were included. All studies were conducted in the last 5 years. Dementia caregivers were the most frequently researched population ($n=7$). Results suggest that mindfulness-based interventions are feasible and acceptable to offer to informal palliative caregivers and may provide benefit, particularly in terms of reducing depression and caregiver burden and increasing quality of life. However, effects were not as robust as findings in the wider mindfulness intervention literature.

Conclusion: This is the first systematic literature review on this topic. Results suggest both feasibility and potential benefit. Further qualitative research is required to explore the outcomes identified by informal caregivers themselves as the reduced magnitude of effect may suggest that we are not measuring the right outcomes in this context. This would inform more sensitive outcome measures for future intervention studies and guide the development and application of mindfulness-based models in this area.

Keywords

Palliative care, informal carers, caregivers, mindfulness, review systematic

What is already known about the topic?

- Caring for a significant other with a palliative illness involves complex challenges that can negatively impact caregiver wellbeing.
- There is a global concern to explore a broader range of caregiver support models, with a focus on proactive, preventative approaches.
- Mindfulness-based interventions are evidenced as providing psychological and physical health benefits for diverse populations and may have application for informal palliative caregivers.

[1]Rural Clinical School, Faculty of Health, University of Tasmania, Burnie, TAS, Australia
[2]Centre for Rural Health, Faculty of Health Science, University of Tasmania, Burnie, TAS, Australia
[3]Charles Darwin University, Darwin, NT, Australia

Corresponding author:
Linda Jaffray, Rural Clinical School, Faculty of Health, University of Tasmania, Australia, Private Bag 3513, Burnie, TAS 7320 Australia.
Email: linda.jaffray@utas.edu.au

What this paper adds?

- This is the first published systematic review of empirical research from around the world into the effects of mindfulness-based interventions for informal palliative caregivers.
- We identified a small number of studies, with findings suggesting feasibility and potential benefit for reducing caregiver burden and depression and increasing quality of life.
- However, effects were not as robust as identified in the wider mindfulness intervention literature, and the majority of studies focused on dementia caregiver populations.

Implications for practice, theory or policy

- Mindfulness-based interventions demonstrate some promise as a low-cost innovative approach to operationalise a fundamental principle of palliative care: holistic family caregiver support.
- Further qualitative research and a focus on caregivers caring in the context of more rapidly progressing disease are warranted.

Introduction

Caring for a family member or friend with a palliative illness can be a positive and rewarding experience.[1,2] However, caregivers also experience significant challenges as they take on the multifaceted, often unfamiliar roles to support complex care, in a setting marked by grief and uncertainty. The adverse effects on caregiver physical and psychological health, including increased rates of depression and anxiety, are well documented in the literature.[3–6] These effects are reported to increase over the disease course, escalate as death approaches[7,8] and can extend to bereavement.[9,10] Caregiver strain has also been shown to adversely impact care recipient experience, as well as the sustainability of homecare.[11] Sustainable homecare, including the support of informal caregivers, is of increasing interest to governments around the world owing to the greater financial burden of in-patient palliative care on health expenditure.[12] With projected increases in people living longer with a greater level of disease burden, many of whom will require palliative and supportive care, informal caregiving in the home setting will gain increasing importance.

While there is a recognised imperative to provide informal caregivers with effective, evidence-based support,[13–15] meeting this goal remains challenging. Rigorous caregiver intervention research to guide clinical practice is required,[16–21] with emphasis on exploring a wider range of interventions to address diverse caregiver need, particularly within the psycho-social domains.[18] Proactive and preventative approaches, actively building on caregiver strengths and self-determination, are also advocated, rather than those that focus on treatment of informal caregivers in crisis.[22]

Mindfulness-based interventions

Mindfulness-based interventions (MBIs) are empowering multicomponent interventions which aim to increase self-efficacy to respond to life stressors and may have application for informal palliative caregivers. Frequently delivered in a group setting, participants are taught, through meditation practice, how to cultivate attention on the 'present moment' rather than being swept away in past or future concerns. Participants learn to sit with and observe their changing field of thoughts, feelings and sensations without judging or seeking to alter the experience.[23] Mindfulness interventions are traditionally delivered over 6–8 sequential weeks lasting for 2.5h. A silent retreat day is embedded in the later part of the programme. In addition, daily mindfulness practice (formal practice) is required, as well as informal practice, in which mindfulness is brought to daily life activities such as walking and communicating with others. Regular practice is considered important in order to cultivate skill and enhance benefit. There are now a diverse range of MBIs with varied protocols and adaptations for particular populations, for example, Mindfulness-Based Cognitive Therapy (MBCT) for depression and anxiety and Mindfulness-Based Cancer Recovery (MBCR) for cancer survivors. Underpinning intervention integrity is the requirement for skilled Mindfulness facilitators who have undergone extensive training and who have an established mindfulness practice themselves.

MBIs are evidenced as providing many physical and psychological health benefits for diverse clinical and non-clinical populations,[24–27] particularly in terms of reducing perceived stress, depression and anxiety. There is emerging research of mindfulness-based programmes for informal caregivers in other contexts. Following an 8-week Mindfulness-Based Stress Reduction (MBSR) intervention, informal caregivers of children with chronic disease had an overall reduction in stress symptoms of 32% and 56% in total mood disturbance.[28] In another study, informal caregivers of adults with chronic conditions had significantly greater reductions in anxiety post-intervention, in depressive symptoms (post and at 3-month follow-up)

and significantly greater self-efficacy scores at 3 months post-intervention, than the control group.[29]

These findings suggest that MBIs may be of benefit to informal caregivers caring in the context of an incurable advancing disease; however, the increased complexity and narrow window of engagement in this setting warrant careful consideration. To our knowledge, there are no published systematic literature reviews exploring this topic; therefore, we sought to systematically investigate the empirical literature and provide a synthesised overview of the effects of MBIs for Informal Palliative Caregivers.

Methods

The study was conducted and is reported here, adhering to the Preferred Reporting Items for Systematic Review and Meta Analyses (PRISMA) guidelines.[30] A Participants, Interventions, Comparisons, Outcomes and Study design (PICOS) review protocol was formulated at study outset with the collaboration of all research members. As this was a systematic review study, ethics approval was not required.

Eligibility criteria

We included primary peer-reviewed studies and thesis, reporting empirical data, on the effects of MBIs for informal palliative caregivers. No restrictions on language, study design, outcome measurements, or comparators were applied. Articles that did not report outcome data, such as study protocols, and conference abstracts that did not progress to full papers were excluded on the grounds that full study details were not able to be evaluated.

Population

An informal palliative caregiver was defined as someone who provided for the physical, emotional or practical support needs of a person with an incurable, progressive illness, based on social connection or kinship. Stage of patient disease was not specified, and illness type was inclusive of both cancer and non-cancer. Studies of professional staff or volunteers employed or managed by an organisation were excluded.

Types of interventions

An MBI was defined as a multicomponent intervention that aimed to teach participants, through meditation practices, how to cultivate attention on the present moment and the changing field of thoughts, feelings and sensations, with qualities of openness and non-judgement. The intervention was required to be delivered in a number of sessions over time, led by a mindfulness facilitator. It could be delivered either in a group or individual setting. No stipulations were put around home mindfulness practice or a retreat day. Adapted mindfulness programmes were included if mindfulness remained the core driver of the intervention and the additional elements did not conflict with the principle tenets of mindfulness. Studies investigating mindfulness as a state or trait, in the absence of a mindfulness intervention, were excluded.

Information sources

The following bibliographic databases were searched from their inception to February 2014: Cochrane Library, CINAHL, MEDLINE, PsycINFO and EMBASE, without language restrictions or search limits. References of included studies and citing articles were also screened to identify additional studies.

Search strategy

A sample of Cochrane Systematic Reviews on palliative care were subject to detailed analysis in respect to search terms used and consultations with CARE SEARCH, a leading Australian palliative care knowledge network occurred. A comprehensive search strategy was then developed and tested in January 2014, prior to running the final strategy. A strategy was formulated for each database separately, using a combination of controlled vocabulary and key words. The search was conducted on 6 February 2014. *See Appendix 1 for the MEDLINE strategy.* The full search strategy is available from the author on request.

Study selection

Upon removal of duplicate records, one reviewer (author L.J.) screened the title and abstracts of identified papers against the inclusion criteria. A reliability check was undertaken by two additional reviewers (authors T.S. and H.B.) who independently screened these records, with differences resolved by papers going to full article review. Full text records were retrieved for more detailed analysis against the eligibility criteria. Authors of conference abstracts were contacted to determine whether they had published full articles pertaining to this work. References of included studies and citing articles were screened and author searches undertaken to identify additional studies.

Data abstraction and analysis

A standardised data abstraction form was used, and for each study, data were extracted for: author, year and country; study design; caregiver characteristics; outcomes; mindfulness type and intervention protocol, as well as class attendance and home practice rates. The classification of mindfulness type was supported by author M.S., an experienced MBSR teacher and practitioner. A narrative

synthesis was conducted, as the small number of studies, diversity of intervention protocols and disparate measures precluded a meta-analysis.

To assess the quality of included studies, the randomised controlled trials (RCTs), the randomised trial and wait-list controlled studies ($n=6$) were assessed using the Cochrane Risk of Bias Tool.[31]

This is a domain-based evaluation of potential bias, advocated by the Cochrane Collaboration, in preference of scoring a quality weight, common in traditional scale-based approaches, which, they argue, have not been well supported by empirical evidence.[32] Following the Collaboration's recommendations, each study was assessed for the potential risk of bias across six domains: selection bias, performance bias, detection bias, attrition bias, reporting bias and other potential biases using the prescribed criteria and guidance. On the basis of this assessment, an indication of low, high or unclear risk was ascribed.

The studies incorporating a qualitative method of inquiry were assessed using the Critical Appraisal Skills Programme (CASP)[33] for qualitative studies. This tool involves assessing the qualitative study using a series of questions that take into account the following: the presence of clear research aims and appropriateness of the chosen methodology; participant recruitment strategy and data collection methods to address these aims; consideration of the relationship between the researcher and study participants; evidence of compliance with ethical standards, rigour of data analysis, clear statement of findings and contribution to existing knowledge and understanding in the subject area. The remaining pre–post studies were not evaluated with a specific tool, as they are acknowledged as inherently having a greater risk of potential bias due to their study design and lack of control group. Study inclusion was not dependent on the assessed level of bias risk or quality, as an inclusive approach of gathering in all the intervention research undertaken in this emerging field of enquiry was considered important.

Results

The search strategy identified 156 references. Following the removal of duplicate records ($n=41$), 115 references were screened against the inclusion criteria by title and abstract. 67 records were excluded in this process – ($n=54$) because participants were not informal caregivers and ($n=13$) because the study was neither an MBI nor involved informal caregivers. In a reliability check for the application of the inclusion criteria, the agreement rate was 86.48%, with differences resolved through consensus. A total of 48 full text records were retrieved for more detailed analysis of which $n=35$ were then excluded. From the 156 records retrieved from the search strategy, 13 articles met the criteria for review inclusion. Three articles by Fegg and colleagues[34–36] reported on different aspects of the same primary study and were treated as one study. Two articles by Whitebird et al. one reporting the primary study and one detailing successful strategies for study recruitment and retention, were also treated as one study. As a result, 13 articles, reporting 10 primary studies, were included in the review. Search results are summarised in the PRISMA flowchart (Figure 1).

Study origins and designs

All studies ($n=10$) were conducted in the last 5 years. Seven studies were conducted in the United States ($n=7$) and one study each from Germany, Spain and Iran. There were a range of study designs, six of which used a control condition. A total of 28 different outcomes were measured, the most common being depression, anxiety, perceived stress, caregiver burden and mindfulness. Diverse measurement scales were used across studies, to assess these constructs. Seven studies employed follow-up measures, ranging from 1 to 6 months post-intervention. Only one study measured outcomes at a more distant time point of 1 year. Two of the 10 studies had a qualitative component.[35,37] Study descriptions and findings are reported in Table 1.

Participants

Across the 10 studies, there were 432 caregiver participants. Dementia family caregivers were the most frequently researched population ($n=7/10$ studies). Patient–carer dyads were included in two studies.[43,45] Caregivers were predominantly female, White, caring for spouses or partners. Across studies, the age of participants ranged from 28 to 88 years. Length of time caregiving was under-reported across studies, with the exception of two studies[39,42] who identified participants as being long-term caregivers (4+ years). Participant characteristics are summarised in Table 2.

MBIs delivered

The type of MBI delivered included MBSR ($n=6$), MBCT ($n=2$), an Acceptance and Commitment Therapy–based model ($n=1$) and one Existential Behaviour Therapy (EBT) approach with mindfulness as its core driver. Nine of the 10 studies used a face-to-face group-based format. Mindfulness protocols varied from four to ten weekly sessions of variable length (1–2.5 h) and were marked by a range of daily home practice requirements (10–45 min). Three studies retained the 'retreat day', a key feature of the MBSR protocol,[39,42,43] but duration varied (4–7.5 h). Five of the 10 studies reported the facilitator's mindfulness qualifications and established self-practice, with varying degrees of clarity.

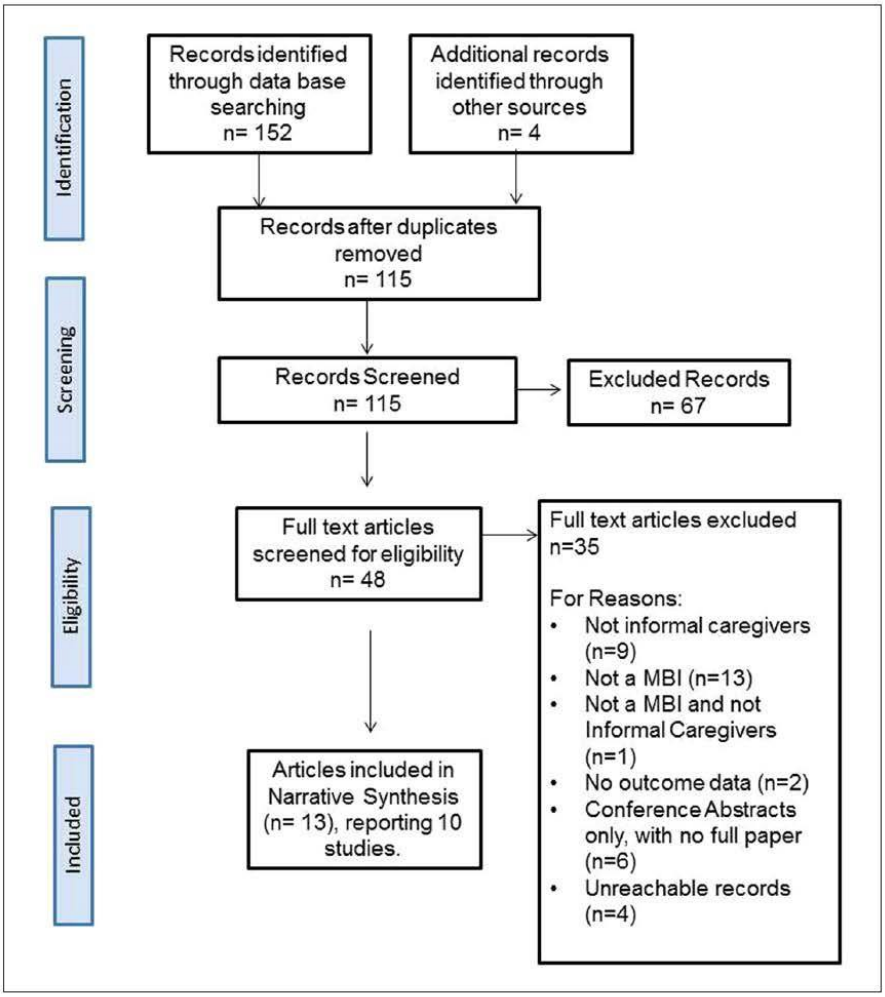

Figure 1. PRISMA flow diagram.

Class attendance, home practice and study retention rates

Six studies reported class attendance rates, ranging from 73% to 93%. Self-reported home practice rates varied across studies; however, in general, this was significantly less than the recommended amount with a further reduction in home practice at follow-up time points. Kogler et al.[34,35] stated that there was a low compliance rate with the recommended amount of formal practice, but higher informal mindfulness practice. Retention rates of participants to full outcome measures appeared high across all studies ranging from 73.35% to 100%.

Quantitative outcomes

Depression. Five of seven studies found a significant effect for depression, including two RCTs and a randomised trial. Four studies found that this significant effect occurred post-intervention,[39–42,44] with two studies also finding a significant effect at 1- to 3-month follow-up.[41,42] One study found that a significant effect for depression emerged at 12-month follow-up.[36]

Quality of life. Two out of three studies found a significant effect for quality of life post-intervention: Norouzi et al.,[41] in a wait-list controlled study, and Fegg et al.,[36] in a randomised trial. Fegg et al.[36] also found significant effects at 1- to 3-month and at 12-month follow-ups.

Caregiver burden. A significant reduction in caregiver burden was found in four out of five studies. Three studies identified this significant effect both post-intervention and at follow-up time points: Hoppes et al.,[37] in a pre–post study, and Franco et al.[40] and Norouzi et al.,[41] both wait-list controlled studies. The pre–post study by Epstein-Lubow et al.[44] found that a significant effect emerged at 4- to 6-month follow-up. In the study by Whitebird et al.,[39] both

Table 1. Data extraction table for included studies.

Author, country, caregivers	Study design	*N* MBI–control (*N** completing full outcome measures)	MBI type, *N* of sessions/ frequency/duration/ recommended home practice	Class attendance/self-reported home practice rates	Outcomes measured	Statistically significant results			
						Post	1- to 3-month follow-up	4- to 6-month follow-up	12-month follow-up
Controlled studies									
Oken et al.,[38] United States Dementia caregivers	RCT education group OR respite-only control	10 (*8)–11 (*11)–10 (*9)	MBCT adapted 7/ Weekly/1.5 h/Home practice NS	Attendance for MBI and control (MBI 0.88 ± 0.05) (education 0.85 ± 0.08) *Home practice*: not reported	Perceived stress	X	NA	NA	NA
					Depression	X	NA	NA	NA
					Fatigue/sleep	X	NA	NA	NA
					Self-efficacy	$p = 0.036$	NA	NA	NA
					Mindfulness	X	NA	NA	NA
					Salivary cortisol	X	NA	NA	NA
					Cytokines	X	NA	NA	NA
					Cognitive function	X	NA	NA	NA
Whitebird et al.,[39] United States Dementia caregivers	RCT education support group control	38 (*35)–40 (*35)	MBSR 8/Weekly/2.5 h and 5-h retreat/ Home practice NS	83% attended at least 7/8 classes 90% retreat day *Home practice*: average of 6.8 sessions per week, 29.4 min per session	Overall mental health	$p = 0.007$	NA	$p = 0.04$	NA
					Depression	$p = 0.005$	NA	X	NA
					Perceived stress	$p = 0.007$	NA	X	NA
					Anxiety	X	$p = 0.02$	X	NA
					Caregiver burden	X	NA	X	NA
					Social support	X	NA	X	NA
Franco et al.,[40] 2010 Spain Dementia caregivers	Wait-list controlled study	24 (*19)–20 (*17)	Meditacio'n Fluir: (Elements of MBSR and ACT) 10/ Weekly/1.5–2 h/ 40-min daily home practice	73% average class attendance *Home practice*: mean compliance 66%; body scan; 72% mindful breathing	Psychological distress	$p = 0.001$	NA	$p = 0.030$	NA
					Caregiver burden	$p = 0.001$	NA	$p = 0.034$	NA
Norouzi et al.,[41] Iran Dementia caregivers	Wait-list controlled study	10 (*10)–10 (*10)	MBCT 8/ Weekly/1.5–2.5 h/ Home practice NS	*Not reported Not reported*	Depression	$p = 0.001$	$p = 0.005$	NA	NA
					Quality of life	$p = 0.001$	X	NA	NA
					Caregiver burden	$p = 0.001$	$p = 0.005$	NA	NA
O'Donnell,[42] United States Neuro-cognitive and dementia caregivers	RCT PMR Control	15 (*11)–13 (*13)	MBSR 8/Weekly/ 2.5 h and 7.5-h retreat/45–60 min, 6 days a week home practice	*Class attendance* MBSR = 93%, PMR Control 94% *Home practice*: MBSR average 57% of recommended practice (PMR 50%) and 48% in following 8 weeks (PMR average of 27%)	Depression	$p = 0.02$	$p = 0.02$	NA	NA
					Perceived stress	X	X	NA	NA
					Self compassion	X	X	NA	NA
					Mindfulness	X	X	NA	NA
					Salivary cortisol	X	X	NA	NA
					Systolic blood pressure	X	X	NA	NA

Table 1. (Continued)

Author, country, caregivers	Study design	*N* MBI–control (*N** completing full outcome measures)	MBI type, *N* of sessions/ frequency/duration/ recommended home practice	Class attendance/self-reported home practice rates	Outcomes measured	Statistically significant results			
						Post	1- to 3-month follow-up	4- to 6-month follow-up	12-month follow-up
Fegg et al.,[36] Germany Informal palliative caregivers (advanced cancer and neurological conditions) Kogler et al.,[34] Germany Kogler et al.,[35] Germany	RT TAU control	81 (*66)–79 (*59)	EBT 2 × half-day sessions on consecutive days, then 4 weekly/22 h total/5 min × 2 daily home practice	*Class attendance* 5.5 ± 0.8 sessions *Home practice*: formal practice (at least 5 min) 3.4 ± 3.8 and informally 5.7 ± 9.2 times a week during intervention with decline in formal practice from T2 to T3 (2.0 + 2.8; $t = 3.7$, $p < 0.01$) and T2 to T4 (1.0 + 1.6; $t = 4.2$, $p < 0.01$, $n = 45$)	Somatisation	X	X	NA	X
					Depression	X	X	NA	$p = 0.04$
					Anxiety	$p = 0.006$	X	NA	X
					Quality of life	SWLS $p = 0.009$, WHOQOL-BREF $p = 0.007$ and QOL-NRS $p = 0.001$	SWLS $p = 0.04$	NA	QOL-NRS $p = 0.002$
					Negative affect	$p = 0.003$	X	NA	$p = 0.003$
					Mindfulness ($n = 130$)	X	X	NA	$p = 0.02$
					Qualitative interviews ($n = 16$)				
Uncontrolled studies									
Hoppes et al.,[37] United States Dementia caregivers	Pre–Post No control	11 (*11)	MBSR low-dose protocol 4/ Weekly/1 h/Home practice NS	*Not reported Not reported*	Caregiver burden	$p < 0.01$	$p < 0.01$	NA	NA
					Hope	$p < 0.01$	$p < 0.01$	NA	NA
					Optimism	X	X	NA	NA
					Mindfulness	X	X	NA	NA
					Qualitative interviews ($n = 8$)				
Hankin,[43] United States MS patients and partners	Pre–Post No control	25 (*22)	MBSR 8/Weekly/2.5 h and 4.5-h retreat/ 45-min formal and 5- to 15-min informal home practice, 6 days a week	*Not reported Home practice*: $n = 8$ practised 3 or more times a week for at least 15 min; $n = 11$ practised less than 3 times a week for 15 min	Anxiety	X	NA	NA	
					Tolerating uncertainty (*Patients. and CGs analysed together*)	$p = 0.016$	NA	NA	NA
					Couple's relationship	X	NA	NA	NA
					Patient's illness uncertainty	X	NA	NA	NA

(Continued)

Table 1. (Continued)

Author, country, caregivers	Study design	*N* MBI–control (*N** completing full outcome measures)	MBI type, *N* of sessions/ frequency/duration/ recommended home practice	Class attendance/self-reported home practice rates	Outcomes measured	Statistically significant results			
						Post	1- to 3-month follow-up	4- to 6-month follow-up	12-month follow-up
Epstein-Lubow et al.,[44] United States Dementia/frail elderly caregivers	Pre–Post No control	9 (*9)	MBSR 8/ Weekly/75 min/ 30-min daily home practice	*Not reported Not reported*	Depression	CES-D $p = 0.001$, SF-12 $p = 0.016$	X	NA	NA
		Caregiver burden				X	$p = 0.007$	NA	NA
		Perceived stress				X	X	NA	NA
		Anxiety				X	X	NA	NA
		Complicated grief (pre loss)				X	X	NA	NA
		General health				X	X	NA	NA
		Mindfulness				X	X	NA	NA
Lengacher et al.,[45] United States Advanced-stage cancer patients and caregivers	Pre–Post No control	26 (*23)	MBSR-C (cancer) 6/ Weekly/2 h alternate class and home practice/ 15–45 min formally and 15–45 min informally daily home practice	91.3% attended at least 2/3 classes *Home practice:* mean compliance of 18.4 min per day. Average practice over 6-week MBSR was 10.0 + 9.0 h	Perceived stress	X	NA	NA	NA
					Depression	X	NA	NA	NA
					Anxiety	X	NA	NA	NA
					Physical and psychological symptoms	X	NA	NA	NA
					Quality of life	X	NA	NA	NA
					Salivary cortisol	X	NA	NA	NA
					IL6	X	NA	NA	NA
					*However, significant decrease in salivary cortisol pre–post MBSR session on week 1 ($p = 0.005$) and week 3 ($p = 0.029$) and IL6 post-week 1 MBSR session ($p = 0.029$).				

MBI: mindfulness-based intervention; RCT: randomised controlled trial; MBCT: Mindfulness-Based Cognitive Therapy; NS: Not stated; NA: Not assessed; X: Not statistically significant; MBSR: Mindfulness-Based Stress Reduction; PMR: Progressive Muscle Relaxation Group; ACT: Acceptance and Commitment Therapy; RT: randomised trial; TAU: Treatment-As-Usual; EBT: Existential Behaviour Therapy; SWLS: Satisfaction With Life Scale; CGs: caregivers; WHOQOL- BREF: World Health Organisations Quality of Life abbreviated assessment; QOL-NRS: Quality of Life Numerical Rating Scale; MS: Multiple Sclerosis; CES-D: Center for Epidemiologic Studies Depression Scale; MBSR-C: Mindfulness-Based Stress Reduction–Cancer.

Table 2. Study participant characteristics.

Author, year, country	Caregiver population	*n*	Caregiver relationship	Age	Gender	Education	Ethnicity
Hoppes et al.,[37] 2012, United States	Dementia caregivers	11	*n*=7 caring for a parent; *n*=4 caring for a spouse	44–81 years, mean age=63.8 years	10 females	x	*n*=11 Caucasian
Oken et al.,[38] 2010, United States	Dementia caregivers	31	*n*=8 caring for a parent; *n*=23 caring for a spouse	Aged=45–85 years	25 females	x	*n*=28 White, *n*=1 African American, *n*=1 Asian
Whitebird et al.,[39] 2012, United States	Dementia caregivers	78	*n*=58 caring for a parent; *n*=20 caring for a spouse, sibling or friend	32–82 years, mean age=56.8 years	69 females	*n*=34 high school/some college; *n*=27 college; *n*=17 graduate school	*n*=76 non-Hispanic White
Franco et al.,[40] 2010, Spain	Dementia caregivers	44	Family caregivers: *relationships not specified*	Age range=34–66 years	31 females	x	x
Epstein-Lubow et al.,[44] 2011, United States	Dementia/frail elderly caregivers	9	*n*=7 caring for a parent; *n*=2 caring for a spouse	Age range=28–73 years, mean age=56.2 years, SD=7.7	9 females	x	*n*=6 Caucasians, *n*=3 African Americans
Norouzi et al.,[41] 2014, Iran	Dementia caregivers	20	Relationship not specified	x	20 females	x	x
O'Donnell,[42] 2013, United States	Neuro-cognitive and dementia caregivers	28	*n*=4 for a parent; *n*=24 caring for a spouse	Age range=66–88 years, mean age=71.6 years, SD=6.7	26 females	*n*=1 some trade/vocational; *n*=1 trade/vocational graduate; *n*=6 some college; *n*=10 college graduate; *n*=6 Master's/ equivalent; *n*=1 Doctoral	x
Hankin,[43] 2010, United States	MS patients and partners	25 patient–carer dyads	*n*=25 caring for partners. (*Carer and patient characteristics reported together*)	Mean age=48.52 years	38 females	x	*n*=37 non-Hispanic White
Fegg et al.,[36] 2013, Germany	Informal palliative caregivers (82.7% cancer, 12.8% neurological)	133	*n*=35 caring for a parent; *n*=82 caring for a partner; *n*=4 caring for a child; *n*=12 other	Age range=23–88 years, 54.5 ± 13.2 years	93 females	*n*=29 none or secondary; *n*=42 vocational secondary; *n*=15 Grammar school; *n*=42 university degree	x
Kogler et al.,[34] 2013, Germany Kogler et al.,[35] 2013, Germany	Bereaved informal palliative caregivers	16	Former life partners of palliative patients (since died, 75% due cancer, 12.5% ALS, 6.3% dementia). *n*=15 married	Age range=38–78 years	10 females	x	x
Lengacher et al.,[45] 2012, United States	Advanced-stage cancer patients and caregivers	26 patient–carer dyads	26 family caregivers. *n*=22 caring for a spouse	Mean age=51.5 years	16 females	*n*=7 high school or less; *n*=10 some college; *n*=9 college or professional degree	*n*=23 White, non-Hispanic

SD: standard deviation; MS: multiple sclerosis; ALS: amyotrophic lateral sclerosis.

the MBI and the education/support group control condition had a statistically significant effect on caregiver burden.

Anxiety and perceived stress. Two out of five studies found a significant effect for anxiety – one study, a randomised trial by Fegg et al.,[36] at post-intervention compared to a treatment as usual control and in an RCT by Whitebird et al.[39] at 1- to 3-month follow-up compared to an education/support group control. One out of five studies found a significant effect for perceived stress at post-intervention, but not at 3- to 6-month follow-up.[39] In the RCT by Oken et al.,[38] a statistically significant effect for perceived stress was identified in both the MBI and the education/support group control, but not the respite control. Similarly, in the RCT by O'Donnell,[42] a significant decrease in perceived stress was identified in both the MBI and Progressive Muscle Relaxation Control.

Mindfulness. One out of five studies measuring mindfulness identified a significant effect. In comparison with a treatment-as-usual (TAU) control, Fegg et al.[36] found that a significant effect emerged at 12 months post-intervention. O'Donnell[42] found that both the MBI and the Progressive Muscle Relaxation Control Group had a statistically significant increase in mindfulness at both post-intervention and at 2-month follow-up.

Other statistically significant results. Significant effects, both post-intervention and at follow-up, were also found for hope, overall mental health and psychological distress. A significant effect for self-efficacy post-intervention for dementia caregivers compared to control conditions of a respite and education/support group and 'tolerating uncertainty' in multiple sclerosis patients and caregivers analysed together were also identified. The remaining outcomes of interest yielded no significant effects (see Table 1 for results).

Qualitative results

Two studies incorporated a qualitative component of inquiry.[35,37] Hoppes et al.,[37] as part of their mixed-method, parallel design study, interviewed 8 of the 11 dementia caregivers who undertook an adapted low-dose MBSR protocol, at 1-month follow-up. Inquiring into the perceived effect of the intervention, four recurrent and related themes were identified: *Increased acceptance* of the care recipient's illness, as well as enhanced acceptance/less judgement towards self and family; *increased sense of presence; increased sense of peace* and reduced stress; and *decreased reactivity*, particularly in terms of response to difficult care recipient behaviour.

Kogler et al.[34,35] interviewed 16/81 former caregivers of palliative care in-patients who received the active intervention of EBT in a randomised trial ($n = 130$). Interviews were conducted 12 months after the last MBI; at this time, all participants were bereaved. Inquiring into the helpful aspects of the EBT intervention, two main categories of benefit were identified: social support and self-regulation. The theme of *social support* encompassed the benefits of interacting with others with shared experiences and included the subthemes of '*self-disclosure*', '*comparison to others*' and '*setting of support*'. The theme of *self-regulation* related to the strategies people used to deal with difficult experiences without becoming overwhelmed by them and included the subthemes of '*mindfulness and acceptance*' which was defined as being aware of current experience with an attitude of acceptance, '*focusing on the positive*' which included positive evaluation of dying, remembering pleasant experiences and searching for sources of strength and '*orientation towards new goals*' which comprised conscious activities, living on one's own and taking care of oneself.

Risk of bias and quality appraisal of included studies

Among the six studies assessed using the Cochrane risk of bias tool,[31] generally there appeared to be a low risk for attrition and reporting bias, with the greatest potential risk associated with a lack of blinding. Under-reporting of methodology resulted in the determination of unclear risk for many bias domains. Studies incorporating a qualitative method of inquiry[35,37] were assessed for quality using the CASP checklist for qualitative studies.[33] Both studies had clearly articulated research aims, and the use of qualitative methodology was appropriate to address these. Both studies were judged to be ethically conducted, used appropriate recruitment strategies, methods of analysis and provided a clear statement of findings which help to advance understanding of the effects of mindfulness training for informal palliative caregivers. In terms of potential bias, however, Hoppes et al.[37] provided little description of the data collection process, and both studies fell short of demonstrating reflexivity.

Discussion

This is the first published systematic review, to our knowledge, of empirical research investigating the effects of MBIs for informal palliative caregivers. Our review found that in comparison to the Mindfulness research for patient populations, which extends over 40 years and increases exponentially each year, the evaluation of MBIs in the setting of informal palliative caregiving is a relatively new field of inquiry ($n = 10$). Drawing definitive conclusions from the studies reviewed is difficult. Effects were not always consistent across studies, which may reflect the diverse interventions, caregiver populations, study designs and use of disparate measures. Based on interview data,

intervention attendance and study retention rates, MBIs appear feasible and acceptable to offer in the context of informal palliative caregiving. Findings also suggest that MBIs may offer benefit for informal caregivers across a range of outcomes, with results more consistent for reducing depression, caregiver burden and increasing quality of life. Qualitative results identified the perceived value of social support, self-regulation, increased acceptance of the illness, self and others, increased sense of presence, peace and reduced stress and reactivity. Studies reported no evidence of harmful effects. As identified in mindfulness studies in other contexts, there was a dilution of effect over time.[46] As most studies reported a decreased rate of practice over time, exploring ways to support ongoing mindfulness practice beyond the end of the intervention is one strategy and supported by the qualitative data.

MBIs

In terms of the MBIs, the majority of studies (9/10) utilised a face-to-face group delivery format; however, the range of interventions and protocols were quite diverse. There was no evidence to suggest that any one MBI was more effective. Emerging research outside the palliative care context is exploring how variance in mindfulness protocols, such as the number, frequency and duration of sessions, impacts intervention outcomes. Other delivery formats such as telehealth and online platforms[47] are also being evaluated with preliminary findings showing comparable benefit to traditional face-to-face group formats.[48,49] This work will be of interest to researchers in the setting of informal palliative caregiving where participants are likely to experience challenges accessing MBIs due to scheduling difficulties, time constraints and not wanting to impact the care recipient by leaving them alone or in respite care. For rural caregivers, travel time and distance are also likely to inhibit access.

Caregiver populations

Seven of the 10 studies included in this review targeted dementia caregivers. More studies are required to explore the experience and effects of MBI for caregivers of patients with more rapid disease trajectories. Issues regarding format, timing, effective engagement, retention and perceived challenges in the setting of more rapidly progressing disease remain unclear.

An important consideration when targeting advanced disease caregivers is how to support participants at different junctures on the end of life caregiving and bereavement journey. Fegg et al.[36] found that a high percentage of their participants were in bereavement (54.9% at baseline and 69.9% at pre-treatment). This study reported that the mixed group composition of active and bereaved caregivers was viewed positively by participants, and while there are obvious complexities to address, the authors point out that it is often in the transition from end of life caregiving to bereavement that people require the most support.[36] This may point to the need to explore adapted mindfulness programmes tailored to address specific areas of need or challenge commonly faced by informal palliative caregivers, as has occurred for other clinical populations such as MBCT for anxiety and depression relapse.

The two studies incorporating patient–caregiver dyads[43,45] reported the least significant effects, compared to the remaining eight caregiver only studies. This may indicate that caregivers require support independent from the care recipient or to talk more openly with others in a similar caregiving situation.

Measuring the right outcomes

While the findings of studies reviewed suggest benefit, the strength of the evidence is weaker than reported in the larger body of mindfulness intervention literature, where there is now robust evidence to support significant effects of MBIs for a variety of psychological and physical health domains.[24] The studies included in this review generally had small sample sizes and were likely underpowered. In addition, in the setting of caring for a significant other with a terminal illness, where stress, and frequently distress, increases over the disease course and escalates as death approaches,[7] there may not be the magnitude of symptom reduction identified in other settings and perhaps nor is it realistic. Alternatively, we may not yet understand the experience of learning Mindfulness while providing informal palliative care and as a result may not be measuring the right constructs. This highlights the role for qualitative research inquiries to more richly explore the perceived effects identified by informal palliative caregivers themselves, which may be missed if we presuppose particular outcomes. Only 2 out of 10 studies included in this systematic literature review incorporated a qualitative aspect of inquiry. A qualitative approach could inform theoretical model development, which is currently identified as a gap in the literature, and guide the selection of more sensitive or appropriate outcome measures. Malpass et al.'s[50] meta-ethnographic review of qualitative research on patient's experience of mindfulness interventions indicates that people experience a perceptual shift in how they related to their illness and a transformation of their sense of self and personal agency.[50] This points to the need to more fully understand how caregivers experience mindfulness training and practice, in order to inform the design of appropriate studies to test MBI's potential benefit.

Mechanisms of action

As with the wider mindfulness literature, understanding about the active components of the MBIs effecting change

is still emerging. The significant effects identified for MBI groups, compared to treatment as usual or wait-list control groups suggest symptom improvement is unlikely to be due to the passage of time. Qualitative data identified that the group environment and peer learning and support are important mechanisms of change; however, the fact that MBI participants had statistically significant improvements in psychological symptoms compared to comparable control conditions matched for time spent with the facilitator, group setting and home practice suggests that other elements specific to the MBI are in play. Five studies assessed for increased mindfulness, using five different measurement scales, yet only one study found a significant increase in mindfulness. This may suggest that the mindfulness measures used were not sensitive enough to detect changes in this setting or alternatively other factors are moderating the effects of the MBI intervention. Understanding the active therapeutic components of these programmes is clearly a critical area for future study.

Study designs

Despite the well-documented challenges of conducting prospective intervention research in palliative care, all the studies included in this review adopted a prospective approach, seven of which undertook follow-up measurements beyond post-intervention. The range of study designs employed was encouraging and included six controlled studies. While the pre–post designs without control groups may have a heightened risk of bias, they have an important role to play in new fields of inquiry, in terms of working through logistics of engagement, implementation, and assessment with the view to inform larger, more rigorous clinical trials.[38]

The generalisability of results of the studies reviewed is impacted by having small, convenience-based, homogeneous samples. Recruiting representative samples is a common methodological challenge in conducting both palliative caregiver intervention research[51] and mindfulness research and remains important to address. Future research would also be advised to report reasons for declined study participation to help inform better design, and the use of similar instruments across studies, to measure outcomes, would enable larger analysis and comparison. More explicit description of methodologies and interventions would also enable higher quality assessment. Facilitators' holding a recognised qualification and an established mindfulness practice is considered fundamental to the integrity of MBSR and its derivative approaches, yet only 5 of the 10 studies reported this.

Strengths and limitations of this review

This study did not include grey literature and as such there may be publication bias against negative results. However, this review was conducted using a systematic methodology as advocated in the PRISMA guidelines. Three authors independently assessed the articles for inclusion using a pre-specified study protocol, anchored in a comprehensive and tested search strategy. This review was also inclusive of papers published in all languages, enabling a view into the world-wide literature.

Given the emergent nature of the research field, we chose to adopt an inclusive approach in which the findings of all studies meeting the review inclusion criteria were reported and discussed. We employed the risk of bias tool and the CASP checklist for qualitative studies to orientate readers to some key methodological considerations, rather than seek to exclude articles on the basis of quality metrics. Furthermore, this review is not making recommendations for clinical practice as the small number of studies with diverse measures and methodologies precludes definitive conclusions at this point in time. Therefore, in this instance, weighing study quality is less critical. The task, instead, becomes one of describing the findings, identifying the key learnings and the issues that require further attention.

Into the future, palliative care services throughout the world will be challenged to demonstrate an ability to more readily translate the central ethos of providing effective holistic family centred care, into practice. Exploring more innovative, proactive approaches that empower caregivers themselves to cultivate a sense of resilience and wellbeing as they take on the complex task of supporting a family member or friend at end of life is also recommended. This review has attempted to pull together the international learning around the effects of MBIs as a potential approach in this setting.

Conclusion

The aim of this review was to systematically identify, evaluate and synthesise the findings of empirical peer-reviewed studies exploring the effects of MBIs for informal palliative caregivers. We identified a small number of studies ($n=10$) with results suggesting that mindfulness interventions are feasible and offer potential benefit to caregivers in this context. The empowering, participatory approach may offer caregivers a proactive way to manage the stress associated with providing care to a significant other during a terminal illness and in bereavement, reducing depression and caregiver burden, enhancing quality of life and a sense of self-efficacy. However, in terms of informing guidelines for clinical practice, there are many questions research has yet to answer. The needs and experiences of caregivers of people with more rapid disease trajectories is an important area for future research. Qualitative inquiry would also elucidate a wider range of potential effects, from the experience and perspective of the caregiver himself or herself. This would assist in defining the mechanisms of action and

help to inform the selection of outcome measures for larger, more robust intervention studies.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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Appendix 1

Medline search strategy February 2014.

1. palliative care [mesh]
2. palliative care [tw]
3. palliat* [tw]
4. palliative [tw]
5. palliative treatment [tw]
6. palliative medicine [tw]
7. palliative therapy [tw]
8. Terminal Care [mesh]
9. terminal care [tw] OR terminal* [tw]
10. terminally ill [mesh]
11. terminally ill [tw]
12. hospice care [mesh]
13. hospices [mesh]
14. hospice care [tw] OR hospice* [tw]
15. 'end of life care' [tw]
16. 'end of life' [tw]
17. death [tw] or dying [tw]
18. ((advanced or end-stage or terminal* [tw])) AND (disease* or illness* or cancer* or malignan* [tw])
19. advanced cancer

20. advanced and cancer [tw] Or advanced and carcinoma* [tw] or advanced and neoplasm* [tw] or terminal* and cancer [tw] or terminal* and carcinoma* [tw] or metastatic and cancer [tw] or metastas* and cancer* [tw] or metastat* and carcionma* [tw] or metastas and carcinoma* [tw] or metastatic and neoplasm* [tw] or metastas* and neoplasm* [tw]
21. liver failure [mesh]
22. liver failure [tw]
23. heart failure [mesh]
24. heart failure [tw]
25. cardiac failure [tw]
26. Kidney failure [mesh]
27. kidney failure [tw]
28. renal failure [tw]
29. amyotrophic lateral sclerosis [mesh]
30. ALS [tw]
31. Motor Neuron Disease [mesh]
32. Motor Neuron disease [tw]
33. acquired immunodeficiency syndrome [mesh]
34. AIDS [tw]
35. Dementia [mesh]
36. dementia [tw]
37. alzheimer Disease [mesh]
38. alzheimer* disease* [tw]
39. parkinson disease [mesh]
40. parkinson disease [tw]
41. neurodegenerative diseases [mesh]
42. neurodegenerative disease* [tw]
43. cardiovascular diseases [mesh]
44. cardiovascular disease* [tw]
45. Stroke [mesh]
46. stroke [tw]
47. cerebrovascular accident* [tw]
48. Multiple Sclerosis [mesh]
49. multiple sclerosis [tw]
50. #1–#49 by OR
51. caregivers [mesh]
52. caregiv* [tw] or carer* [tw] or care giv* [tw]
53. family or families or parent* or friend* or relative* or spouse* or partner* or husband* or wife or wives or child or children or close person* or significant other* [tw] AND (care* or caregive* or care giv*) [tw]
54. #51 or #52 or #53
55. Mindfulness [mesh] or Mindfulness [tw]
56. #50 AND #54 AND #55

Appendix 3: Ethics Approval Letter - Phase One

Office of Research Services
University of Tasmania
Private Bag 1
Hobart Tasmania 7001
Telephone + 61 3 6226 7479
Facsimile + 61 3 6226 7148
Email Human.Ethics@utas.edu.au
www.research.utas.edu.au/human_ethics/

HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK

UTAS

02 December 2014

Professor Timothy Skinner
C/- Head of School, School of Psychological and Clinical Services, Charles Darwin University.

Sent via email

Dear Professor Skinner

REF NO: H0014541
TITLE: The perceived benefits and key considerations in providing mindfulness based programs and teaching for informal palliative caregivers: exploring the perspectives of mindfulness facilitators, practitioners and researchers

Document	***Version***	***Date***
Consent Mindfulness Facilitator and Researcher Interview		Oct 2014
Low Risk Application		
Mindfulness facilitator and Researcher Invitation		
Participant Information Sheet Mindfulness Facilitators practitioners and Researchers		Oct 2014

The Tasmanian Health and Medical Human Research Ethics Committee considered and approved the above documentation on **28 November 2014** to be conducted at the following site(s):

Rural Clinical School Burnie

Please ensure that all investigators involved with this project have cited the approved versions of the documents listed within this letter and use only these versions in conducting this research project.

This approval constitutes ethical clearance by the Health and Medical HREC. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approvals of other bodies or authorities are required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

All committees operating under the Human Research Ethics Committee (Tasmania) Network are registered and required to comply with the *National Statement on the Ethical Conduct in Human Research* (NHMRC 2007 updated 2014).

Therefore, the Chief Investigator's responsibility is to ensure that:

(1) The individual researcher's protocol complies with the HREC approved protocol.

(2) Modifications to the protocol do not proceed until **approval** is obtained in writing from the HREC. Please note that all requests for changes to approved documents must include a version number and date when submitted for review by the HREC.

(3) Section 5.5.3 of the National Statement states:

Researchers have a significant responsibility in monitoring approved research as they are in the best position to observe any adverse events or unexpected outcomes. They should report such events or outcomes promptly to the relevant institution/s and ethical review body/ies and take prompt steps to deal with any unexpected risks.

The appropriate forms for reporting such events in relation to clinical and non-clinical trials and innovations can be located at the website below. All adverse events must be reported regardless of whether or not the event, in your opinion, is a direct effect of the therapeutic goods being tested.
http://www.research.utas.edu.au/human_ethics/medical_forms.htm

(4) All research participants must be provided with the current Patient Information Sheet and Consent Form, unless otherwise approved by the Committee.

(5) The Committee is notified if any investigators are added to, or cease involvement with, the project.

(6) This study has approval for 4 years contingent upon annual review. A *Progress Report* is to be provided on the anniversary date of your approval. Your first report is due 28 November 2015. You will be sent a courtesy reminder closer to this due date.

(7) A *Final Report* and a copy of the published material, either in full or abstract, must be provided at the end of the project.

Should you have any queries please do not hesitate to contact me on (03) 6226 6254.

Yours sincerely

Jude Vienna-Hallam

Digitally signed by Jude Vienna-Hallam
DN: cn=Jude Vienna-Hallam, o=University of Tasmania, ou=Ethics Unit, email=Jude.ViennaHallam@utas.edu.au, c=AU
Date: 2014.12.02 10:57:13 +11'00'

Ethics Administrator
Research Integrity and Ethics Unit
Office of Research Services
University of Tasmania
Private Bag 01
Hobart Tas 7001
T +61 3 6226 6254
http://www.utas.edu.au/research-admin/home

Appendix 4: Ethics Approval Letter - Phase Two

Social Science Ethics Officer
Private Bag 01 Hobart
Tasmania 7001 Australia
Tel: (03) 6226 2763
Fax: (03) 6226 7148
Katherine.Shaw@utas.edu.au

HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK

UTAS

2 March 2016

Dr Jessica Woodroffe
Launceston Clinical School
University of Tasmania

Student Researcher: Linda Jaffray

Sent via email

Dear Dr Woodroffe

Re: FULL ETHICS APPLICATION APPROVAL
Ethics Ref: **H0015513 - The lived experience of learning or using a mindfulness based approach as an informal palliative caregiver**

We are pleased to advise that the Tasmania Social Sciences Human Research Ethics Committee approved the above project on 1 March 2016.

This approval constitutes ethical clearance by the Tasmania Social Sciences Human Research Ethics Committee. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approval of other bodies or authorities is required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

Please note that this approval is for four years and is conditional upon receipt of an annual Progress Report. Ethics approval for this project will lapse if a Progress Report is not submitted.

The following conditions apply to this approval. Failure to abide by these conditions may result in suspension or discontinuation of approval.

1. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval, to ensure the project is conducted as approved by the Ethics Committee, and to notify the Committee if any investigators are added to, or cease involvement with, the project.

2. Complaints: If any complaints are received or ethical issues arise during the course of the project, investigators should advise the Executive Officer of the Ethics Committee on 03 6226 7479 or human.ethics@utas.edu.au.

3. Incidents or adverse effects: Investigators should notify the Ethics Committee immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.

4. Amendments to Project: Modifications to the project must not proceed until approval is obtained from the Ethics Committee. Please submit an Amendment Form (available on our website) to notify the Ethics Committee of the proposed modifications.

5. Annual Report: Continued approval for this project is dependent on the submission of a Progress Report by the anniversary date of your approval. You will be sent a courtesy reminder closer to this date. **Failure to submit a Progress Report will mean that ethics approval for this project will lapse.**

6. Final Report: A Final Report and a copy of any published material arising from the project, either in full or abstract, must be provided at the end of the project.

Yours sincerely

Katherine Shaw
Executive Officer
Tasmania Social Sciences HREC

Appendix 5: Recruitment Sources - Phase One

Agency / Person Targeted for Recruitment	Description	Location
Mindfulness Sector		
Private practitioners advertising mindfulness training (n=4)	Provider of MBIs	Local (within Tasmania) and Nationally (Australia)
Mindfulness-integrated Cognitive Behaviour Therapy Institute	Provision of MBI	Local (within Tasmania)
Open Ground Australia	Provider of MBIs	National (Australia)
Mindfulness Centre	Provider of MBIs	National (Australia)
Mindfulness at Monash	Provider of MBIs	National (Australia)
Mindfulness Training Institute Australasia	Provider of MBIs	International
Centre for Mindfulness in Medicine, Health Care and Society, University of Massachusetts USA	Provider of MBIs and research	International
The OASIS Institute, USA	Provider of MBIs	International
Centre for Mindfulness Research and Practice (CMRP) Bangor University UK	Provider of MBIs and research	International
Oxford Mindfulness Centre (OMC), UK	Provider of MBs and research	International
Institute for Mindfulness South Africa	Provider of MBIs	International
Palliative Care Sector		
Tasmanian Association for Hospice and Palliative Care (TAHPC)	Palliative care and hospice information and advocacy group	Local (within Tasmania)
Specialist Palliative Care- Tasmanian Health Service across three regions (n=3)	Government palliative care service	Local (within Tasmania)
Department of Medicine University Malaya Medical Centre, Kuala Lumpur Malaysia	Palliative care service	International
Buddhist and Zen Hospice organisations.	Hospice	National (Australia)
Melbourne Zen Hospice	Hospice	National (Australia)
The Karuna Hospice	Hospice	National (Australia)
Upaya Institute and Zen Centre, Santa Fe, NEW MEXICO	Hospice	International
Cancer Councils across three different states (n=3)	Cancer support service for patients and families	Local (within Tasmania) and Nationally (Australia)
Olivia Newton John Cancer and Wellness Centre	Cancer care and wellness centre	National (Australia)

Agency / Person Targeted for Recruitment	Description	Location
Palliative Care Sector continued		
Department of Psychosocial Resources, University of Calgary, CANADA	Cancer care service	International
Gawler Foundation	Wellness centre	National (Australia)
Australian Centre for Grief and Bereavement	Grief and bereavement services	National (Australia)
Carers Tasmania across three different regional services (n=3)	NGO carer support service	Local (within Tasmania)
eHospice	A global online news / information resource for end-of-life care	Nationally throughout (Australia) and internationally
CareSearch	A leading Australian palliative care knowledge network	National (Australia)
Australian Psychology Association (APA)	Professional association and network for psychologists	Local (within Tasmania)
Australian Association of Social Workers (AASW)	Professional social work association and network	Local (within Tasmania)

Appendix 6: Study Invitation Letter - Phase One

UNIVERSITY of TASMANIA | FACULTY OF HEALTH

An Invitation

To participate in a research study into the

Perceived benefits and key considerations in providing

Mindfulness-based programs and teaching for informal palliative caregivers

My name is Linda Jaffray. I am a PhD candidate with the University of Tasmania's Rural Clinical School in Burnie, Tasmania, Australia. I am seeking to explore the perspectives of mindfulness facilitators, practitioners and researchers who have experience in supporting informal palliative caregivers. Outcomes of this study will inform a follow-up study involving informal palliative caregivers themselves.

Informal palliative caregivers can be defined

> *as those who provide a caring or support role to a significant other with an incurable, progressive disease in receipt of palliative care services or in the last 12 months of life.*

You may have delivered a mindfulness-based program

- *Specifically, for a group of informal palliative caregivers or;*
- *had participants in more generic groups who had been or were currently providing informal care in a palliative context;*
- *or alternatively, you may have used mindfulness- based approaches or teaching in a one to one therapeutic setting with informal palliative caregivers.*

You may be a researcher who has studied mindfulness-based approaches for informal palliative caregivers.

What is involved?

We are seeking your participation in a semi-structured qualitative interview, lasting about an hour, at a time and place convenient to you. If you are interested in learning more about the project or wish to participate please contact me. I will provide you with a participant information sheet and a consent form for you to sign and return, prior to arranging an interview.

We appreciate it is an increasingly busy world, with people having to juggle large workloads, however we value your experience and perspectives on this topic and would welcome your participation.

Contact details: **Linda Jaffray, (*BSW). PhD Candidate***

Rural Clinical School Burnie I School of Medicine I Faculty of Health I University of Tasmania, Australia.

Email: linda.jaffray@utas.edu.au *Phone*: (03) 6430 5906 or (international callers) +613 6430 5906

Appendix 7: Participant Information Sheet - Phase One

UNIVERSITY of TASMANIA | FACULTY OF HEALTH

PARTICIPANT INFORMATION SHEET

For the Research Project: -The perceived effects and key considerations in providing mindfulness-based approaches for informal palliative caregivers: exploring the experience and perspectives of mindfulness facilitators, practitioners and researchers.

The purpose of this document is to inform interview participants involved in this research of the aim, method and anticipated outcome of the research for informed consent.

Dear Sir /Madam,

You are invited to participate in a research project which will be exploring the perceived effects of mindfulness-based approaches for informal palliative caregivers. For the purpose of this study, Informal palliative caregivers are defined as: *those who provide for the practical, physical or emotional support needs of a significant other with an incurable, progressive disease in receipt of palliative care services / or in the last* 12 *months of life, usually undertaken from the basis of kinship or social connection.*

Mindfulness based approaches are defined as: *A facilitated or practitioner led program, delivered in a number of sessions over time, with the aim of teaching participants through meditation practice how to cultivate attention on the present moment and observe the constantly changing field of thoughts, feelings and sensations without judging or seeking to alter the experience.*

This research project is being undertaken by Linda Jaffray (PhD Candidate, University of Tasmania) under the supervision of Professor Timothy Skinner (Psychological and Clinical Services, Charles Darwin University and adjunct professor, University of Tasmania), Miranda Stephens (Rural Clinical School, University of Tasmania), Dr Heather Bridgman (Centre for Rural Health, University of Tasmania.

What is the purpose of this study?
To explore the perceived benefits and key considerations of providing mindfulness-based approaches for informal palliative caregivers. This particular study seeks the perspectives of mindfulness facilitators, practitioners and researchers who have experience in supporting informal palliative caregivers. Outcomes of this study will inform a follow-up study involving informal palliative caregivers themselves.

W**hy have I been invited to participate?**
You (or a representative of your organisation) were selected as a possible participant in this study for your role as a mindfulness facilitator, practitioner or researcher and the experience you have in supporting informal palliative caregivers. Please note however, that your involvement in this

research is entirely voluntary and that you are free to withdraw your involvement at any time during the research process. Should you decide to withdraw your participation this will not be viewed.

What will I be asked to do?

You will be asked to participate in a semi-structured interview lasting about an hour. Interviews will occur at a time and place that is convenient to you and be an opportunity for you to share your experience, perceptions and ideas in a supportive and respectful environment. The interview will be audio recorded so the researchers can accurately capture the information being provided. These recordings will then be transcribed word for word. We will ensure that all your information is confidential by removing anything from the transcripts that could identify you. This will be done prior to the analysis of the transcripts by the research team.

Are there any possible benefits from participation in the study?

There is a well- documented need to identify effective, evidence-based interventions to support informal palliative caregivers, with particular attention required on proactive, as opposed to crisis-orientated models. Emerging research suggests that Mindfulness based interventions, may have beneficial application in this setting, however more empirical work is required to understand the range of effects mindfulness approaches may have for this population, the active ingredients producing effect, as well as understanding what challenges may be involved. This invitation to participate in this study provides an opportunity to contribute your experience and perspectives in order to advance understanding of these issues and inform future more robust intervention studies. There are however, no tangible benefits to you personally for being involved in this study.

Are there any possible risks from participation in this study?

The focus of this research is on your perceptions of the effects mindfulness-based approaches have for informal palliative caregivers and will not elicit any information of specific individual patients / clients or seek participants to disclosure their own personal experiences. However, it is acknowledged that in discussing issues of terminal illness, death and bereavement people can experience upset. If this occurs you will have the opportunity to end the interview and information on a range of support options and referral to relevant support agencies or professionals will be provided. Beyond this there are no foreseeable risks associated with participation in this research project.

What if I change my mind during or after the study?

Please note that as a voluntary participant in this study you are free to withdraw at any time without explanation. You just contact a member of the research team on one of the phone numbers listed at the end of this information sheet. Any information that can be attributed to you can be withdrawn from the study.

What will happen to the information when this study is over?

Please be assured that participant confidentiality and anonymity are key goals of the research team. Steps will be taken to ensure the safeguarding of the data and your identity. After the interviews audio-recordings will be transcribed, assigning pseudonyms to each of the participants so that any piece of information or direct quote cannot be assigned to any particular individual, all hard and electronic copies of data will be kept secure for a period of 5 years. Throughout the research, hard copies will be stored in a locked filing cabinet at the UTAS RCS and will be archived at the end of the project in a secure research data archive store at the RCS. Electronic copies will only be accessible by the research team via password protected files within the UTAS computer system.

How will the results of the study be published?

Study results will be made available as a report which we are happy to provide to you if requested. Results may also be published in relevant academic journals, on the RCS website (located at: http://www.utas.edu/au/rural-clinical=school/) or in conference papers. As we will be de-identifying all of the information before analysis and using a process of thematic analysis, any information or quotes used in these publications will be general or technical in nature and will not be attributable to you.

What if I have questions about this study?

If you have any questions regarding this research project, please feel free to contact any member of the research team. Contact details are:

Linda Jaffray	(03) 6430 5906 or (international callers) +613 6430 5906
Professor Timothy Skinner	+ 618 8... ....
Dr Heather Bridgman	(03) 6324 4 048 or (international callers) +613 6324 4048
Miranda Stephens	(03) 6430 4550 or (international callers) +613 6430 4550.

This study has been approved by the Tasmanian Health and Medical Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 62267479, (International Callers) +613 6226 7479 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number **H0014541**.

If you are willing to participate in this research project, please complete the attached Informed Consent Form and return it to the research team.

Please keep this information sheet for your reference

Thank you for your time and support.

Prof. Timothy Skinner, Head of School I School of Psychological and Clinical Services I Charles Darwin University and Adjunct Professor I School of Medicine I Faculty of Heath I University of Tasmania.

Linda Jaffray, Rural Clinical School I School of Medicine I Faculty of Health I University of Tasmania

Dr Heather Bridgman, Centre for Rural Health I Faculty of Health Science I University of Tasmania

Miranda Stephens, Rural Clinical School I School of Medicine I Faculty of Health I University of Tasmania.

Appendix 8: Participant Consent Form - Phase One

UNIVERSITY of TASMANIA | FACULTY OF HEALTH

CONSENT FORM

Title of Project: **The perceived benefits and key considerations in providing mindfulness-based approaches for informal palliative caregivers: exploring the experience and perspectives of mindfulness facilitators, practitioners and researchers.**

Please Tick

1. I am satisfied that I understand the purpose of this study, the expectations regarding my involvement and my participation is given voluntarily. ☐

2. I understand that I will take part in an interview that will take around 60 minutes and be conducted at a time and place of my convenience. ☐

3. I understand that the interview conversations will be audio-recorded and that when it is typed out, word for word, that any identifying information will be removed so my confidentiality will be ensured. ☐

4. I understand that there will be no direct benefit to me from participating in this study. ☐

5. I understand that my involvement in this research should not affect my relationship with other professionals or my patients. ☐

6. I understand that I am free to withdraw from the research at any stage. My withdrawal will not affect my legal rights, my relationship with the hospital or any health professionals. ☐

7. I have been advised that this research will be conducted in accordance with the latest versions of the National Statement on Ethical Conduct in Human Research 2007 and applicable privacy laws. ☐

8. I understand that I am not giving up my legal rights by signing this consent form and that I will be given a signed copy of this consent form and the accompanying information sheet. ☐

9. I understand that I can request a transcribed copy of my interview and will have one week to make any changes to the transcript ☐

Participant Name_____

Signature_____ Date_____

Duly Authorised Person (if applicable)_____

Signature_____ Date _____

INVESTIGATOR:

I have explained this research and the implications of participation in this project to this volunteer and I believe that the consent is informed and that he / she understand the implications of participation

Investigator Name _____

Signature_____ Date _____

Appendix 9: Recruitment Sources – Phase Two

Agency or Person Targeted for Recruitment	Description	Location
Mindfulness Sector		
Mindfulness-based organisations and private providers advertising mindfulness training (n=5)	Provider of MBIs	Tasmania
Palliative Care Sector		
Inpatient hospice care unit	Hospice facility	Tasmania
Inpatient palliative care beds in general hospital	General hospital	Tasmania
Specialist Palliative Care Service - Tasmanian Health Service in three different regions (n=3)	Government palliative care service	Tasmania
Hospice @ Home in two different regions (n=2)	NGO support service for palliative patients and their families	Tasmania
Hospice volunteer services in two different regions (n=2)	Palliative caregiver respite service	Tasmania
Care Beyond Cure	A grass-roots community development, palliative support & health promotion program	Tasmania
Carers association in three different regions (n=3)	NGO carer support service	Tasmania
Oncology service	Hospital oncology department	Tasmania
Cancer support organisation n= 3 sites	NGO cancer support organisation	Tasmania
Community health centre (Nursing and Social work Departments)	Community health service	Tasmania
Health promotion network	Service provider health promotion network	Tasmania
Tasmanian Association of Hospice and Palliative Care (TAHPC)	A state association and advocacy group for hospice and palliative care	Tasmania
Community library in two different regions (n=2)	Community library	Tasmania
Green Health	Alternative health centre	Tasmania
Australian Psychology Association (APA)	Professional psychologist association and network	Tasmania
Australian Association of Social Workers (AASW)	Professional social work association /network	Tasmania

Appendix 10: Study Invitation Letter - Phase Two

UNIVERSITY of TASMANIA | FACULTY OF HEALTH

An Invitation

To take part in a research project exploring:

The Learning and Use of Mindfulness Whilst Caring for a Family Member or Friend with a Terminal Illness or After Caregiving, in Bereavement.

My name is Linda Jaffray. I am a PhD candidate with the University of Tasmania's Rural Clinical School in Burnie, Tasmania.

I am doing a study which seeks to *understand how learning and using Mindfulness impacts the experience of caring for a family member or friend with a palliative illness, or the experience of bereavement following caregiving.*

There is limited research in this important area, especially research that seeks to talk to people who have first-hand experience of learning mindfulness in these settings. My study aims to understand these issues better in order to inform the thinking about and development of support programs for family caregivers in palliative care.

I would like interview people who:

- are 18 years or older, living in Tasmania;
- able to speak and understand English;
- are currently or have previously provided care and support to a family member or friend with a palliative illness in the last 12 months of life;
- are currently or have previously learnt a mindfulness-based approach such as, but not limited to, Mindfulness based stress reduction (MBSR), Mindfulness based cognitive therapy (MBCT), Mindfulness-incorporated cognitive behaviour therapy (MiCBT).

What is involved?

If you agree to participate in the research, you will be asked to participate in an interview lasting between 1 and 2 hours. The Interviews will occur at a time and place that is most convenient. The interview is an opportunity for you to share your experience and ideas with a researcher in a supportive and respectful environment.

If you are interested in learning more about the project or wish to participate please contact me. I can provide you with an information sheet about the project and explain how you can consent to be involved.

We value your experience and perspectives on this topic and would welcome your participation.

Contact details: **Linda Jaffray, (*BSW). PhD Candidate***
Rural Clinical School Burnie I School of Medicine I Faculty of Health I
University of Tasmania, Australia. Email: linda.jaffray@utas.edu.au Phone: (03) 6430 1652

Appendix 11: Participant Information Sheet - Phase Two

UNIVERSITY of TASMANIA | FACULTY OF HEALTH

<u>This information is for interview participants</u>.

The Lived Experience of Learning and Using a Mindfulness-based Approach as an Informal Palliative Caregiver.

Invitation

You are invited to participate in research which is ***exploring the experience of learning and using mindfulness either whilst caring for a family member or friend with a terminal illness or after caregiving, in bereavement***.

This research project is being undertaken by Linda Jaffray (PhD Candidate, Rural Clinical School) at the University of Tasmania under the supervision of Dr Jess Woodroffe (Division of Students and Access and School of Medicine), Professor Timothy Skinner, Miranda Stephens and Dr Heather Bridgman.

What is the purpose of this study?

This study aims to understand how learning and using Mindfulness impacts the experience of caring for a family member or friend with a palliative illness and/or the experience of bereavement following caregiving. The current research is limited in this area, especially research that seeks to talk to people who have first-hand experience of learning mindfulness in these settings.

This study is seeking to talk with people who are:

- 18 years or older, living in Australia
- able to speak and understand English
- who are currently or who have previously provided care and support to a family member or friend with a palliative illness or in the last 12 months of life;
- who are currently or have previously learnt a mindfulness-based approach such as, but not limited to, mindfulness-based stress reduction (MBSR), mindfulness based cognitive therapy (MBCT), mindfulness integrated cognitive behaviour therapy (MiCBT).

Why have I been invited to participate?

We are interested in talking with people who have had the experience of learning and using mindfulness either whilst caring for a family member or friend with a terminal illness or after caregiving, in bereavement.

You may have found information about this study in a newsletter, on an information board, or on the web or perhaps another person or service provider may have passed on this information to you, thinking you may be interested in participating.

Your participation in this research is voluntary. There are no consequences if you decide not to participate and it will not affect your relationship with any services or professionals that either you or for the person you are caring for are receiving.

What will I be asked to do?

If you agree to participate in the research, you will be asked to participate in an interview lasting between 1 and 2 hours. Interviews will occur at a time and place that is convenient to you. The interview is an opportunity for you to share your experience and ideas in a supportive and respectful environment. The interview will be audio recorded so the researcher can accurately capture the things that you talk about. These recordings will then be transcribed word for word. Any identifying information will then be removed from the transcripts which could identify you as a participant. You will be provided with an opportunity to review your transcript and two weeks to provide any corrections should you feel it is necessary.

Are there any possible benefits from participation in this study?

By sharing your experience of learning and using mindfulness either during or after palliative caregiving you have the opportunity to inform understanding about the potential value and challenges of learning mindfulness in these situations. This will help services to understand the elements that are important when it comes to developing mindfulness-based approaches for other people who are caring in a palliative situation and / or in bereavement.

What if I become upset in the interview?

Whenever we reflect on and talk about our experiences of supporting someone we care about with a palliative illness it is normal that we may experience a range of emotions. I am a social worker who has worked a lot with people who express their grief and sadness and I believe that I have the skills to interview sensitively.

However, if at any time through the interview you become upset, we can stop the interview and you can decide whether or not you would like to continue. I will also offer you contact details of support services if you wish to be referred. Please find the attached list of available supports should you decide that you would like to access them. I will also offer you the opportunity to receive a follow-up phone call in the next couple of days, from myself or another member of the research team.

What if I change my mind during or after the study?

Please note that as a voluntary participant in this study you are free to withdraw at any time without explanation. You just contact a member of the research team on one of the phone numbers listed at the end of this information sheet. Any information that can be attributed to you can be withdrawn from the study.

What will happen to the information when this study is over?

Please be assured that participant confidentiality and anonymity are key goals of the research team. Steps will be taken to ensure the safeguarding of the data and your identity. After the interviews, audio-recordings will be transcribed, assigning pseudonyms to each of the participants so that any piece of information or direct quote cannot be assigned to any particular individual, all hard and electronic copies of data will be kept secure for a period of 5 years. Throughout the research, hard copies will be stored in a locked filing cabinet at the UTAS RCS and will be archived at the end of the

project in a secure research data archive store at the RCS. Electronic copies will only be accessible by the research team via password protected files within the UTAS computer system.

How will the results of the study be published?

Study results will be made available as a report which we are happy to provide to you if requested. Results may also be published in relevant academic journals or in conference papers. As we will be de-identifying all of the information before analysis any information or quotes used in these publications will be general or technical in nature and will not be attributable to you.

What if I have questions about this study?

If you have any questions regarding this research project, please feel free to contact any member of the research team. Contact details are:

Linda Jaffray (03) 6430 1652 Dr Jess Woodroffe (03 63 243088)

Professor Timothy Skinner + 618 8946 6408 Dr Heather Bridgman (03) 63 244 048

Miranda Stephens (03) 64 304550

This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on +61 3 6226 6254 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number H0015513.

If you are willing to participate in this research project, please complete the attached Informed Consent Form and return it to:

Linda Jaffray; Private Bag 3513 Burnie, Tasmania, 7320 or scanned and via email to linda.jaffray@utas.edu.au. Alternatively, you can phone on 03 64 301652 to discuss things further.

Please keep this information sheet for your reference

Thank you for your time and support.

Appendix 12: Participant Consent Form - Phase Two

UNIVERSITY of TASMANIA | FACULTY OF HEALTH

Study Title: The Lived Experience of Learning and Using a Mindfulness-based Approach as an Informal Palliative Caregiver.

This consent form is for interview participants

1. I agree to take part in the research study named above.
2. I have read and understood the Information Sheet for this study.
3. The nature and possible effects of the study have been explained to me.
4. I understand that the study involves me taking part in an interview that will take between 1 – 2 hours and be conducted at a time and place convenient to me and the researcher.
5. I understand that my interview will be audio-recorded and then typed out word for word, but that any information identifying me as a participant will be removed.
6. I understand that I can request a transcribed copy of my interview and will have two weeks to make any changes to the transcript.
7. I understand that my participation is voluntary, and I can withdraw from the interview at any time without prejudice
8. I understand that all research data will be securely stored on the University of Tasmania's premises for five years from the publication of the study results and will then be destroyed unless I give permission for my data to be stored in an archive.

   I agree to have my study data archived.

   Yes ☐ No ☐
9. Any questions that I have asked, have been answered to my satisfaction.
10. I understand that the researcher(s) will maintain confidentiality and that any information I supply to the researcher(s) will be used only for the purposes of the research with the one exception being if I was to disclose an intent to harm myself or others. In this instance I understand that this risk may need to be shared with others to ensure the safety and wellbeing of myself and others.
11. I agree that the research data gathered for the study may be published provided that I cannot be identified as a participant.
12. I would like to receive a letter or email at the end of the project that outlines the main findings of the study and provide my contact details below for this purpose:

Participant's name: _____

Participant's signature: _____

Date: _____

Statement by Investigator

☐ I have explained the project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet where my details have been provided so participants have had the opportunity to contact me prior to consenting to participate in this project.

Investigator's name: _____

Investigator's signature: _____

Date: _____

Appendix 13: Semi-structured Interview Schedule - Phase One

Semi-structured Qualitative Interview Questions of Mindfulness Facilitators	
Key concerns / activities	**Questions, possible phrasing**
Check participant has read and understood information sheet and I have already received a signed and witnessed copy of the consent form / or get the participant to sign in my presence.	*"Thank you for taking the time to talk with me today. I would just like to check that you have read the information sheet I provided and whether you had any questions about what participation in this study involves. Thank you for your signed consent form"* (if already returned) or get participant to sign consent form in my presence. *"I am just confirming that you understand and agree to our conversation being recorded today? This will make sure that I can capture accurately what you are saying. It will be de-identified so you that no one will be able to trace back to you what you have said. If you would like a copy of your transcript to check for accuracy, please let me know. I understand that time is precious, so I will keep our interview within an hour today".*
Clarify the focus of my research and who I mean by informal palliative caregivers	"My research is interested in the effects of teaching mindfulness to informal palliative care givers: - by informal palliative caregivers I am talking about people who are caring for a family member or friend with an incurable, progressive disease receiving palliative care /or in the last 12 months of life"
Gain an understanding of the mindfulness work they have done with IPCG	**I was wondering if would like to start by telling me a bit about your experience of teaching mindfulness to informal palliative caregivers?**
Determine format: Individual / group	If it was group based, was it specifically targeting informal palliative caregivers? If not, how would you describe the group population *(all different ailments, people with depression, people caring for someone with cancer)*
If Group Population, Did it target INPCGs?	What were your impressions on how the group composition worked / didn't work?
Establish where the learning of mindfulness fitted in the caregiving trajectory.	Were people actively caregiving at the time of learning mindfulness, or had the patient / care recipient died and they were therefore bereaved at the time of learning mindfulness? Have you had the experience of teaching mindfulness to people who subsequently become caregivers? Did they talk about the effects learning mindfulness had for them in terms of their caregiving role/ bereavement?
Engagement	How did you engage them / referral pathways? Were there difficulties with this and if so what were they?
Protocol	In not already explained: *"Can you tell me a bit about the mindfulness program you offered in terms of the type of mindfulness, number of sessions, where it was held etc?*
Timing	*From your experience when would you think the most optimum time is for engaging informal palliative caregivers in mindfulness training?*
Retention	*What do you regard as being important in terms of retaining caregivers' participation in a mindfulness program?*
Access	*What do you regard as the barriers for IPCG in terms of accessing a mindfulness program?*
Motivation for offering MBI to IPCG	If program was targeting IPCG "*What lead you to offer mindfulness to informal palliative caregivers?*
Prior assumptions about what benefit it might offer / potential challenges and negative effects	*Before providing the training, what did you think mindfulness might offer people in the context of palliative caregiving?*

	Before providing the training in mindfulness, did you have any reservations that it might be too challenging or cause negative affects?
Observation of effects / participant report of effects	
Perceived benefits, value	*What did you actually observe and what did people say to you in terms of what was helpful / beneficial about learning mindfulness?*
Perceived challenges	*Did you observe people encounter challenges in learning mindfulness - what were these?*
Perceived harmful / negative effects	*Did you observe people experiencing negative or harmful effects - what were these?*
Important components	*What do you think were the important aspects of the intervention underlying the effects?*
Key considerations in developing / providing MBI for IPCG	*What would say are the important considerations in developing and providing mindfulness programs to informal palliative caregivers?*
Interview Participant Characteristics	Gender Country Occupational setting *Do you practice mindfulness yourself?* Length of time practising mindfulness and delivering Mindfulness Interventions *I am interested in knowing your background training in mindfulness, can you tell me about this?*

Appendix 14: Semi-structured, Intensive Interview Schedule - Phase Two

UNIVERSITY of TASMANIA | FACULTY OF HEALTH

Semi-structured Interview Questions / Prompt sheet

Introduction

Thank you for agreeing to speak with me today and share some of your thoughts and reflections. I am hoping that you will find the interview today to be a respectful and relaxed conversation. I will be asking you some questions about your experiences of learning and using mindfulness and your experience of caring for a family member or friend with a palliative illness. There are no right or wrong answers. I would just be really interested to learn more about how mindfulness may or may not help people who are supporting someone they care about in the last 12 months of life.

I am used to talking with people who are supporting and caring for a family member or friend towards the end of life. I have worked in palliative care as a social worker for 12 years, prior to coming into research. I have also cared for and experienced the death of my Dad and my grandmother. I feel that those experiences have provided me with the skills to be sensitive in our conversation today. I remind you that you can feel free to take a break or stop the interview at any time and if there are some questions that you would prefer not to answer that is okay too.

Can you tell me a bit about how you came to learn mindfulness?

Prompts: How did you find out about it? Who was offering it and where?

What did it involve?

Prompts: Was mindfulness taught in group format or one to one? How was it delivered: in person or over the phone/ internet etc.? What type of mindfulness was it? How many sessions was it taught over? Was there a home practice element?

How did you initially feel about learning mindfulness?

Prompts: What did you expect it may be like? Had you done anything similar before?

In terms of time frames, when did you learn mindfulness, for example was it before you began caring for your family member or friend / whilst you were caring for them or (if the person has died) **after the person died?**

Would you like to tell me a little bit about the person you are /were caring for?

Prompts: What was your relationship to them? What type of illness did they have? How long have you been caring / did you care, for them?

Do you / did you have any services that were supporting you in your caring role?

I was wondering how you feel about the word 'carer' or 'caregiver'. Is that the how you would name or describe your role or would you have another way of talking about that?

What is it / was it like to learn mindfulness considering what you were / are going through at this stage in your life?

Have you experienced positive things or benefits from learning and using mindfulness?

If yes, what are these positive outcomes / benefits?

Prompts: What effect did these positive things have in your life? Can you give me any examples? Did other people notice these positive things?

What did these positive things mean for you in your life?

If no, do you have a sense of why you didn't experience any positive things or benefits?

Have you encountered any challenges to learning and using mindfulness?

If yes, what are these challenges?

Prompts: Did it come naturally, or did you find it hard in the beginning? What effect did they have on your life? Can you give me any examples?

If no, why do you think it is that you didn't encounter any challenges? What do you think helped you learn and use mindfulness?

Has learning mindfulness effected the way you look at things or respond to things now?

If yes, in what way? What has this meant for you?

Has your learning and use of mindfulness had an impact on others around you?

If yes, in what way?

Prompts: Who do you think it impacted? Can you give me an example?

Can you tell me or explain in your own words what it means to be mindful?

Prompts: Can you give me an example of a time / event in which you feel you were being mindful or not being mindful? What was happening? What were you doing or saying? What effect did this have on you? What effect did this have on others?

What place does mindfulness have in your life now?

Prompts: How often do you use or practice mindfulness; i.e. regularly, only when things are really difficult or not using it much?

Thinking about your own experiences of mindfulness do you have any suggestions on how we might best offer mindfulness to others in similar situations?

Prompts: From your own experience is there anything you can think of that could have been improved or done differently?

Is there any reason you think that mindfulness shouldn't be offered to family carers, caring for someone with a palliative illness or in bereavement?

Is there anything else you would like to share (good or bad) about mindfulness for family caregivers, caring at the end of life / or afterwards in bereavement?

Concluding questions

So that I have a way of describing the characteristics of the people that I interviewed, would you mind if I asked you how old you are? You can give me an age or if you would be more comfortable I could say an age range like 18-29 for example and you can say which age group your age falls in?

Would you also mind telling me what the highest level of schooling was that you went to?

[High school, Trade qualification, University, post graduate university degree].

Bringing the interview to a close

I would like to finish by thanking you for how generous you have been with your time and willingness to share your experiences with me today. I hope that your story and insights will help shape the thinking about the place mindfulness has to support family caregivers in a palliative setting. As we talked about earlier. I will take away this recording, type it up word for word, but then remove any identifying information. If you would like to receive a copy of your transcript or typed interview you can request this and you can have two weeks make any changes to it if you feel you need to. As I mentioned, I have a list here for you to take with you of the support services that you can contact should you want to access support.

Thank you again. It is important to me to be able to talk with people, like yourself, with firsthand experience of learning mindfulness as a caregiver and to make sure your voice, experience and insights have a central place in the research.

Appendix 15: Memo 1 - Interviewing Molly at Home

MEMO 1 - INTERVIEWING MOLLY AT HOME

The home setting was chosen by Molly who was actively caring for her husband Peter who had chronic end-stage lung and heart disease. Molly was finding it increasingly difficult to leave Peter alone because he was becoming progressively unwell. For her an interview at home enabled the possibility of participating in the study. Peter was home at the time of our interview. Molly greeted me at the door and then took me into the lounge room where Peter was sitting and introduced us. Peter looked unwell. He was pale, thin and had trouble catching his breath when talking or coughing, which he did frequently. Molly checked if Peter needed anything before leading me into the kitchen to begin our interview.

Throughout my interview with Molly we would frequently hear Peter coughing in the lounge room and trying to catch his breath. I looked at her a few times as if to see whether she needed to go to him. Most the time Molly would briefly acknowledge the noise from the lounge room by lifting her gaze, pausing for a moment as if to assess if she needed to do anything, before continuing talking. Sitting there with Molly in her own house listening to the sounds of her life - of Peter coughing and struggling with his breath provided greater insight into how she encountered the reality of her husband getting sicker each day.

Interviewing Molly at home also enabled me to more fully appreciate the physical tasks that had fallen to her since Peter had become increasingly unwell and their impact, much more than if I had only had her words to get a sense of this. For example, I could see the animals that needed tending, the wood that needed to be carried and stacked. I could look out the windows to see the large steep gardens and imagine how they would call for her attention and energy every day.

During the interview Peter came into the kitchen two times. He came in to get a cup of tea and then returned towards the end of the interview to get the medications he had forgotten to take at lunchtime. Molly apologised for Peter coming into the kitchen, regarding them as 'interruptions'. To me, this was just life happening in and around our interview and constituted important data, rich with context: a window into Molly's world of caregiving.

Appendix 16: Memo 2 - Interviewing Bill at Home

MEMO 2 - INTERVIEWING BILL AT HOME

I interviewed Bill at his preference, in his own home; the most beautiful little place by the sea, whose front garden went straight down to the beach. He was 87 years old with Parkinson's Disease. As a fisherman, Bill spent most of his life being close to the water. Having a home by the sea was something that he clearly valued. His home was also where he had cared for his wife who had died of cancer eight months earlier. Interviewing Bill in his home gave me a richer sense of both himself and his wife. In our conversation, he pointed out the artwork that he and his wife had collected in their international travels. He was able to show me photographs of his grandchildren. I also met his little dog who was a source of strength and hope for him in his bereavement and his motivation to walk two kilometres along the beach each day, as he promised his wife that he would continue to do.

At one point in the interview Bill pointed towards the day-bed by the window. The sun was streaming in on the bed. It looked like a beautiful spot from which to look out on the seascape beyond the garden. He told me that his wife spent a lot of time on that day-bed looking out over the ocean. He also told me that that was the very spot that she died after lunch one afternoon. Bill made the comment that she was 'a lady' to the end and "slipped away quietly" never wanting to cause a fuss. We both just looked at the daybed for a while as he attempted to steady his emotions. I wouldn't be able to get the same depth of understanding about his experience, his sense of loss, how his home space held both beautiful and painful moments for him, had I not been in his home environment for the interview.

Appendix 17: Support Services Information Sheet - Phase Two

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SUPPORT SERVICES

For Immediate Support Contact

Life Line who provide 24/7 telephone counselling

Life Line phone contact: **13 11 14**

Or you can access their online one-on-one '*Crisis Support Chat'*

www.lifeline.org.au/Get-Help/Online-Services/crisis-chat

Beyond Blue provides a 24-hour counselling service with trained mental health professionals. Call **1300 22 4636** or you can chat online or email them, accessible at this webpage https://www.beyondblue.org.au/get-support

Mental Health Crisis Hotline Tasmania (available 24 hrs, 7 days)

Phone: **1800 332 388**

Additional Services Include

Cancer Council Ph: **13 11 20** for confidential telephone information and support services for the cost of a local call – mobile charges apply.

GriefLine Ph: **1300 845 745** for free counselling and support to individuals and families: telephone support, online counselling or one on one counselling. Or you can access http://griefline.org.au

Talk to your GP and ask for a referral to a **Psychologist.** This may be able to be bulk billed or it may incur a gap fee. A list of psychologists to look for one in your region can be found here: http://www.psychology.org.au/FaP/

CatholicCare offer grief counselling (fee dependent on income): Hobart **6278 1660** Launceston **6332 0600** Devonport **6423 6100** Burnie **6431 8555.**

Your local **Palliative Care Service** may also be able to connect you with counselling and support.

Launceston: **(03) 6777 4544**

Burnie: **(03) 6440 7111**

Hobart**: (03) 6224 2515**

Appendix 18: Line by Line Coding of a Data Extract from a Caregiver Interview

Example of Initial, Line by Line Coding from a Caregiver Interview	
Molly: I started doing that *[listening to the mindfulness smart phone app*] ten minutes for ten days and immediately I noticed a dramatic difference. **LJ**: In what way? **Molly**: Well I was much more focused. I was more energetic. Um I had a clearer sense of purpose. **LJ:** Wow. **Molly**: It was quite dramatic, those first ten days. **LJ:** Had you anticipated that? **Molly:** No, I didn't anticipate that. No. **LJ**: Were you open to it or sceptical or? **Molly:** I was surprised. I was surprised and amazed [*laughs*] because I felt really different. **LJ**: So, can you describe what was happening for you then, like when you started listening to it [the mindfulness app] what was happening for you? In what way was it dramatic or transforming? **Molly**: Yeah. Yeah, it's not so much when I was doing the meditation it was the rest of my life, you know. I just felt more purposeful, more you know, instead of sort of um, I don't know, getting through the day in a sort of haphazard sort of way, with a lot of sitting around doing nothing, I felt like this is what I have to do and got up and did it and was more efficient and you know more purposeful. So, it was really good hmm. And more energetic, yeah. And the other thing I didn't react to stuff as much. Like when bad things happen, and you know Peter is carrying on um and you know being in a way that I don't like, let's say. Then I was able to let that wash over me like a river, in the same way as you know when you are doing meditation and the thoughts come and you don't make judgements about the thoughts. You just observe the thoughts and let them pass. So, I was able to take that kind of approach to the stuff that was happening around Peter as well. So you know, when he was complaining or being miserable or whatever I could just sort of not make judgements about what he was saying and not feel like I had to do anything about it or react to it. I could just observe it [laugh] like your thoughts and just think 'oh that is just the river'.	Starting mindfulness Undertaking ten minutes practice each day Noticing 'a dramatic difference' Positive Differences: Becoming 'more focused' Having more energy. Experiencing clearer sense of purpose Noticing a 'dramatic' effect early Unexpected, not expecting such an effect Feeling surprised at effect Experiencing self in a different way *[Interviewer probing for more nuanced description / example]* Noticing positive effects outside of meditation practice – 'in the rest of my life' Feeling 'more purposeful' *[difficulty finding right words or descriptors]* Doing the activities of the day with more awareness, drive Contrasting experience with previous experience 'sitting around doing nothing' More purposeful enables greater efficiency Feeling more energised – appraising effects as positive Noticing self not being as reactive as normal Noticing self not reacting to difficult experiences or husband's difficult behaviour Letting things / husband's behaviour and attitude 'wash over me like a river' Practising same skill as those practised in meditation sessions Allowing thoughts to come Refraining from judging thoughts Observing thoughts and letting thoughts pass Not attaching or reacting to husband's complaining or 'being miserable' Not judging husband's words or him Freeing self from feeling responsible to change things Just watching as an event happening outside and separate to self that comes and goes.

LJ: Had you ever had the experience of being able to do that before? **Molly:** No but I wanted to. I could see that it was a good thing, but I hadn't actually been able to get there, but now I feel I can, yeah, much more easily. Because it sorts of links to that thing of when you are meditating on your thoughts and you don't attach to your thoughts. **LJ:** Wow, that's fairly powerful. **Molly**: hmm, hmm, mm *[Peter coughing loudly in the next room as we speak]*	*[interviewer trying to determine if these were new experiences for molly]* Experiencing these positive effects for first time Wanted these experiences, but had not been able to 'get there' Feeling resourced now to bring these positive experiences into her life. Practising mindfulness, helps being mindful in daily life Learning and practising not attaching to your thoughts. *[Interviewer acknowledgment of this as 'powerful' – Molly agrees]*

Appendix 19: Progression of Data Analysis Through Focused Coding

Data Extracts Related to the Overarching Process: The Value and Benefit of MBIs for Informal Palliative Caregivers	Initial Coding	Memo-Writing & Constant Comparison	Focused Coding
'When you are meditating on your thoughts and you don't attach to your thoughts' (Molly) 'Slowing down my breathing, thinking about the air coming into my body and how am I feeling. It seems to ground me a little bit, so it [thoughts] certainly stops for a period of time. It does distract my mind for a time. I stop the repetitive thoughts' (Laura). 'Just to step back and notice that their mind is running through all of those different thoughts and ideas and solutions to the problem they're facing, but to not be so caught up right in amongst it all and just be a little bit more mindful of their thinking, mindful of their approach to managing whatever they're confronted with at any particular time' (F12). 'Mindfulness is a perspective thing- your pain is not you, your thoughts are not you' (F4) 'They [caregivers] are not so lost in their thoughts or fears about the future' (F1)	<u>Describing positive effects on thoughts</u> Untangling from thoughts Grounding and resting the mind Stepping back from being caught up in thoughts Becoming more aware of thoughts / mindful of effect on action Getting perspective on and relocating self in relation to thoughts = more empowered Less overwhelmed by or lost in thoughts	*There was a common sentiment underlying participant description of MBIs impact across the domains of thoughts, feelings and events / time.* *A sense of shift in how caregivers come to relate to their thoughts, feelings and the events around them.* *There was a sense of an empowered movement from being caught up in / infused with thoughts, feelings and what was happening around them to occupy moments of feeling more calm, present and grounded.*	Stepping back from enmeshment (in thoughts, feelings and events) Stepping into more grounded space: *Moments of respite and calm* *Increased awareness of thoughts, feelings and events* *Increased ability to make informed choices about actions*
'It distances me a bit and you can remain calm and not get involved and that's good' (Molly). 'They are a lot calmer themselves; that's the thing I mostly see over the eight weeks' (F4) 'They learn how to tolerate affect, investigate it, treat it as an object to be investigated, rather than be subject to it' (F8) 'You're not spending your whole time wound up in all the other possible thoughts and feelings that could be around there and being aware- just being aware of what's going on. Because I guess before you're aware of it you're just completely caught up in it. So when you've got the ability to step back a bit it's really helpful' (Sarah) 'Mindfulness helps them cope with the emotional roller coaster ride...to help deal with the carer stress of being with someone who is suffering' (F6) 'Mindfulness helps them sit with the full range of emotions and their relationship to those perceived negative feelings does start to change' (F10)	<u>Describing positive effects on emotions</u> Getting perspective on feelings Becoming calm Not being so caught up in / overwhelmed by feelings Stepping back and becoming aware of feelings and thoughts Supporting coping, dealing with stress Accepting and being with difficult emotions / changed way of relating to difficult emotions		
Mindfulness really helps by centring yourself and bringing yourself back to the now rather than being scattered like I seem to be a lot' (Laura). 'It (mindfulness) helps them to be present and more fully engaged with the process of supporting the person who is dying' (F1) 'Mindfulness helps them to arrive in a place they have never been before' (F10) 'The very act of seeing is also sort of what I call an intimate distance- it's touching what's going on but it's not being caught up in it. So there's insight but there's calmness' (F9). 'Mindfulness helps to learn how to see things as they are, like to discern things accurately because you can't navigate the world if you don't see things as they are' (F4)	<u>Describing positive effects on events and time</u> Grounding and engaging in the present moment as opposed to being pulled into imagined future events Increasingly aware, but less overwhelmed by what is happening around them Orientating them Gaining perspective Increasingly aware / able to make more considered choices		

Appendix 20: Memo 3 -Evolving the Theoretical Concept 'Repositioning Self'

MEMO 3 - THEORETICAL MEMO-WRITING TO ARRIVE AT 'REPOSITIONING SELF'

Throughout this whole analysis process, I have been grappling to distil and name this enduring and central category in the data that has a strong connection to all categories of benefit offered by mindfulness in end-of-life caregiving. I began by noticing that participants were continually talking about this sense of mindfulness helping them to 'untangle' from thoughts and feelings that ordinarily overwhelm and immobilise them. Similarly, they also conveyed mindfulness as providing them with a way to extract themselves from being caught up in and consumed by difficult events occurring around them, but not in a way of avoiding or disconnection from their experience. I initially coded this data separately as being about either 1) thoughts, 2) feelings, 3) events but then came to see that actually it was the process of untangling or stepping back from these experiences that was the key aspect of this benefit. The data was also pointing to a larger idea of caregivers coming to relate differently to these experiences as a result of stepping back from them somewhat, there was a sense of gaining perspective, becoming less overwhelmed, being calmer and clearer in relation to the things they were confronted with. The category of 'relating differently to thoughts, feelings and events' captured the properties of this data better. However, as I talked to more people, analysed more transcripts I realised that there were two key processes underpinning this larger process of learning to relate differently to their experiences. There was a process of 'stepping back from enmeshment' and there was a 'stepping into a more grounded, present moment space'. I have still felt that there is something missing in terms of capturing the essence of this category – something about the way in which my participants have voiced that mindfulness doesn't make difficulties in caregiving or life more broadly disappear or ultimately change that much, but their relationship to them is the thing that is altered – in 'brief but important moments' that a make a big difference to a sense of empowerment. I have refined this category in a more theoretical way as '<u>Repositioning Self' which I have come to understand as</u>:

> *brief but important moments of stepping back from being enmeshed and overwhelmed by thoughts and emotions and challenging situations, to occupy a calmer, more grounded, clearer seeing space. The new space opened-up by mindfulness is not fixed and permanent, caregivers come in and out of this space. Additionally, it does not vanquish not ultimately really change the difficulty that caregivers encounter in caregiving and their lives more broadly. However, what is changed is how caregivers relate to their experiences: there's less distraction, avoiding, wrestling and feeling overwhelmed, and more acknowledging and 'being with' difficulty and gaining a sense of themselves as being bigger than the issues they are faced with, an increased sense of empowerment. The way in which participants speak of this process is almost as if it is a 'meta-process', in itself, that has flow on effects to or is related in some important way to other benefits of learning mindfulness in end-of-life caregiving.*